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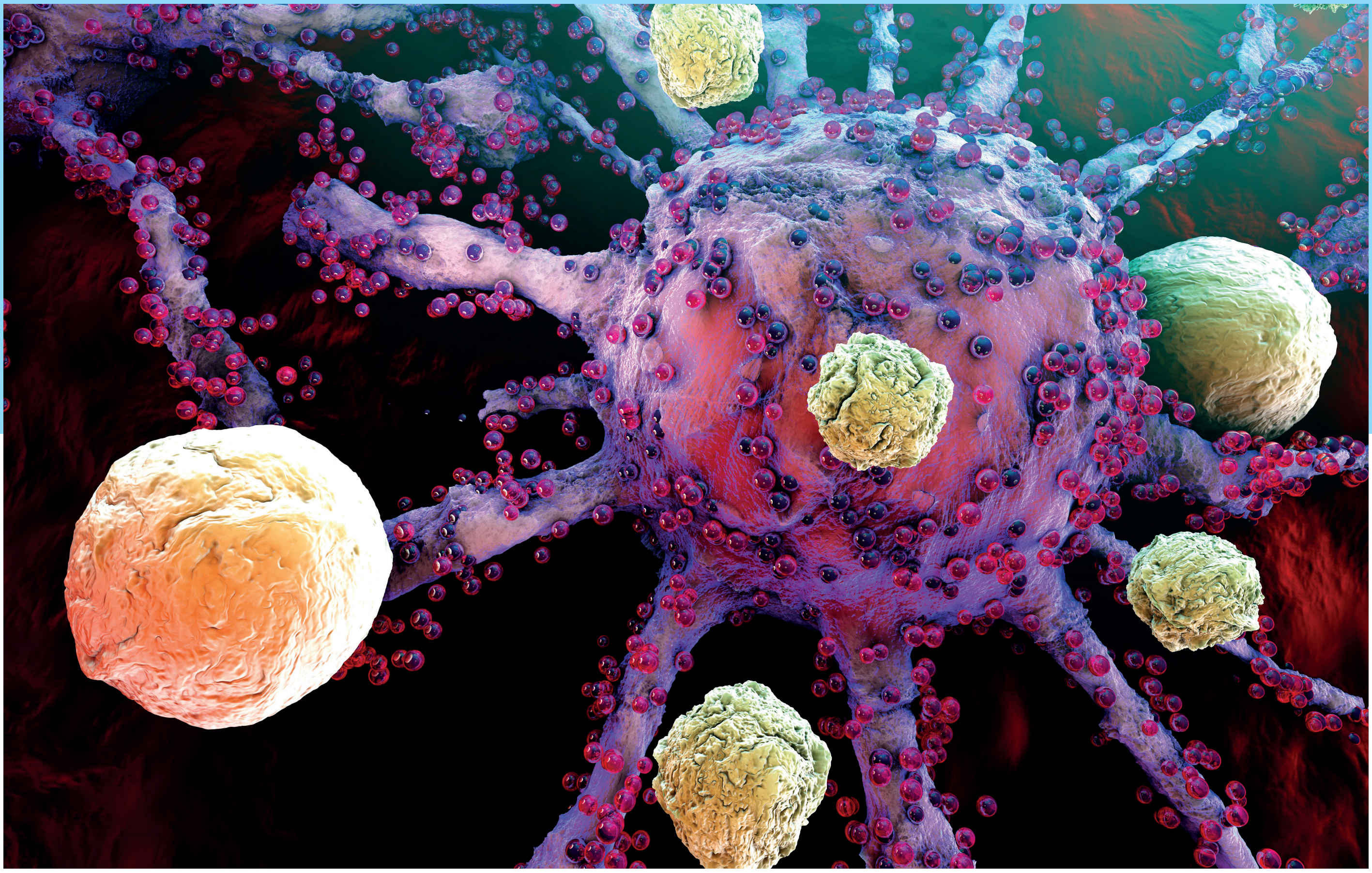

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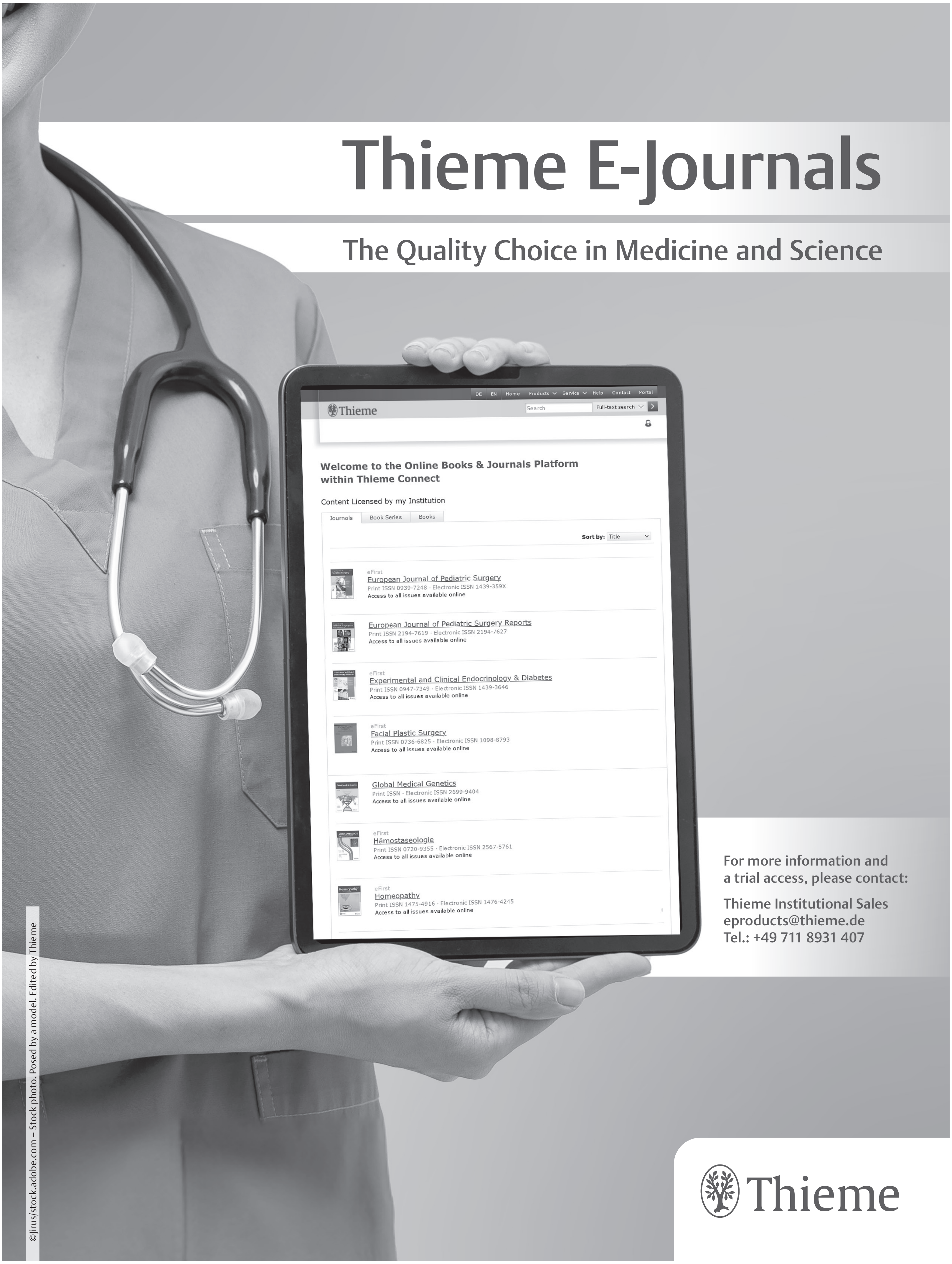

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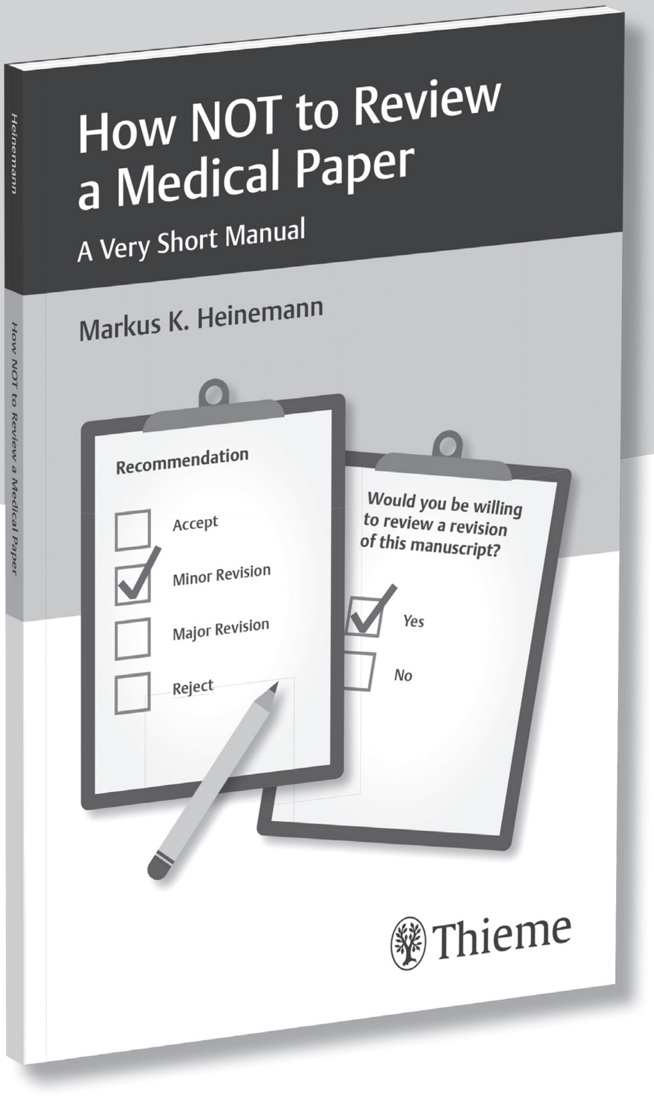

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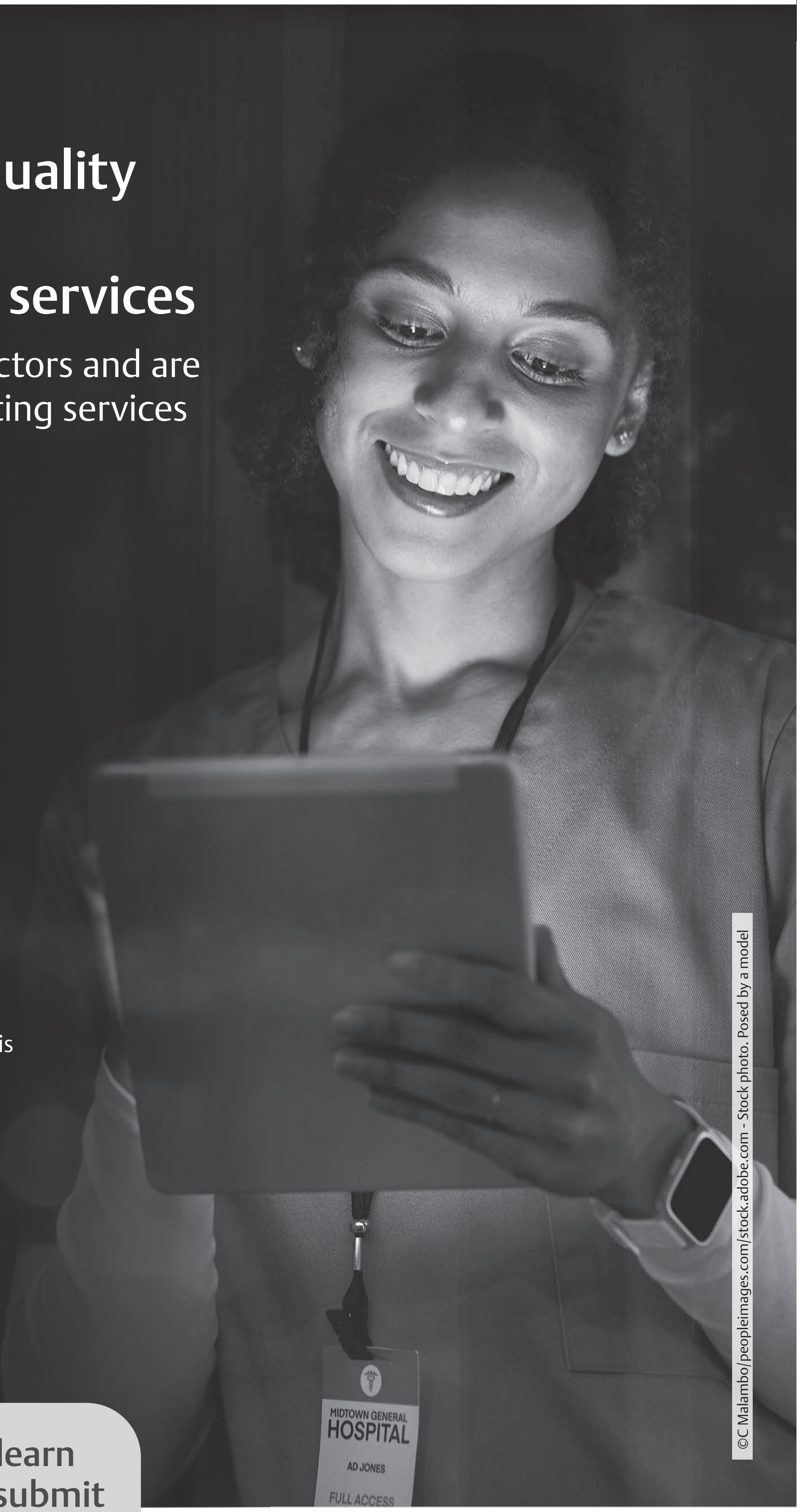

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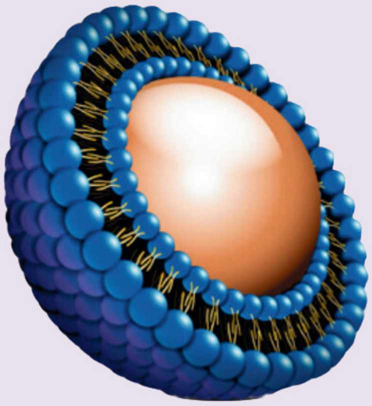

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3 X
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Editorial

Special Edition on Psycho-Oncology, *Indian Journal of Medical and Paediatric Oncology*

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Psycho-oncology was defined in 2002[1] by one of the founders of this discipline, Dr. Jimmie Holland, as "the psychological, social, behavioral, and ethical aspects of cancer," incorporating:

- the psychological responses of patients, their families, and carers to cancer at all stages of the disease, and
- the psychological, behavioral, and social factors that may influence the disease process.

Psycho-oncology, by its very nature, is interdisciplinary and multifocal, with interests in many areas, including patient-centered and family-centered care,[2] shared decision-making,[3] medical ethics,[4] medical communication,[5] behavioral medicine,[6] psychiatry/psychology interventions,[7] symptom control and supportive care,[8] end-of-life care,[9] and psycho-neuroimmunology.[10]

The importance of psycho-oncology research and practice has been well-recognized internationally, due to the existential, physical, and psychosocial challenges of cancer diagnosis, treatment, and treatment-related side effects.[11,12] Such challenges result in high rates of distress, psychological morbidity (such as anxiety and depression), and suicide among the cancer population.[13] The largest study to date comparing mental health rates in cancer patients with that in the general population[14] reported a 1.3-fold increased prevalence rate for any mental disorder, and a 2-3-fold increased prevalence rate of depression in cancer patients. The suicide rate in the first 6 months after a cancer diagnosis has been reported to be seven times than that of the general population.[15] Practical difficulties (such as financial, travel, and work-related challenges), the need to take in a large volume of unfamiliar and threatening information and make difficult decisions in the context of uncertainty, and for some, advice to change long-held behaviors, add to this burden.[11,12] Furthermore, mental health challenges can extend into survivorship, in response, for example, to ongoing treatment or long-term side effects.[16]

Therefore, the incorporation of psychosocial assessment and management into routine cancer care has been internationally advocated, with many organizations issuing clinical practice guidelines and pathways for cancer psychosocial care.[17–21] Many systematic reviews[22–24] have concluded that psychosocial interventions are effective in reducing psychological morbidity in cancer patients, while a recent analysis of population-based data from the U.S. noted a reduction in suicide rates since the introduction of better psychosocial care into cancer centers.[15]

However, the majority of research papers and clinical guidelines have been published in affluent Western countries such as the United States of America, Canada, the United Kingdom, the Netherlands, and Australia. Low- and middle-income countries (LMICs) face significant additional challenges in cancer care, including low literacy and health literacy among their populations and fewer resources available for health services.[25] Currently in India, while a number of institutions provide professional degrees in psycho-oncology[26] and psycho-oncology professionals are employed in comprehensive cancer centers, pain and palliative units, and nongovernmental organizations across the country, separate psycho-oncology-focused services are still lacking.[26] While psychosocial care has been recognized as a priority within the palliative care subspecialty in India and other LMICs, evidence of implementation into cancer care within these countries is poor.[20]

Cultural differences in approaches to health care and family responsibilities may also impact the applicability of Western models of care.[27] For example, in India and other Asian countries, the family may be accorded cancer decisional control to protect the patient from distressing information and ensure decisions are in the best interests of the family as a whole.[27] Thus, the primarily patient-centered models of care used in the West may not be appropriate in India.[27] In the light of the differences discussed above, the current special issue on

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psycho-oncology research and practice in India and Indonesia is very welcome, to provide alternative perspectives and solutions within psycho-oncology that match the resources and cultural preferences of LMICs.

This special issue encompasses a wide range of psychosocial oncology research. It includes descriptive work documenting common mental health conditions presenting to cancer psychosocial services, and in children with cancer in Indonesia; coping styles used in response to different mental health presentations; and unmet needs in oral cancer survivors. The results of these studies can guide the provision of mental health services in India and LMIC more broadly.

Several papers focus on distress and burnout in cancer health professionals, particularly during the coronavirus disease pandemic. Overall, levels of distress and burnout were high, particularly in those with less than 10 years of experience, and who had previously experienced mental health problems.[28] These papers highlight the importance of supporting the supporters, and ensuring that staff have access to appropriate and destigmatized support services.

One small randomized controlled trial is reported of an exercise intervention for oral cavity cancer patients, finding it to be effective in reducing fatigue and fatigue impact. Exercise has been highlighted as an effective intervention for fatigue in randomized trials internationally,[29] but this impact has not been previously evaluated in India in this population.

Finally, two papers focus on the delivery of care, the first documenting the most common cancers in India mapped against the delivery of services, highlighting disparities between need and services. The second focuses on the role of integrated cancer services in providing optimal care to people with cancer presenting with complex problems. The role of allied health such as nutritional and mental health care was highlighted.

Overall, this body of work will contribute to the growing discipline of psycho-oncology in India and LMIC. Moving ahead, a focus is required on feasible, acceptable, and sustainable interventions that will make a difference to the quality of life of cancer patients and their families in LMICs.

Conflict of Interest
None declared.

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The Crucial Role of Psychosocial Research for Patients and Caregivers: A Narrative Review of Pediatric Psycho-Oncology Research in India

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Abstract

The focus of pediatric cancer research in India has largely been medical and clinical, with little focus on psycho-oncological aspects. Receiving a cancer diagnosis can be life altering for both the patients as well as their families and points to a need for psycho-oncological research. The present narrative review examined original articles on pediatric psycho-oncology research conducted in India particularly in the past two decades. There is promising research in various domains such as survivorship and quality of life, patient needs and psychosocial concerns, communication between health care providers, patients, and caregivers, parent and caregiver needs including psychosocial support and information, as well as some intervention-based studies. With much of the research being conducted within clinical setups through surveys and retrospective data, psychosocial issues faced by patients and their families are discussed along with physical, logistical, and financial concerns, while forays into intervention-based research are still in primary phases but show potential in terms of outcomes and feasibility. There is need for more methodologically rigorous research rooted in strong theoretical foundations, culturally sound models, and with evidence-based examination of all stages and stakeholders involved in providing and receiving care in pediatric cancer.

Keywords
- psycho-oncology
- pediatric cancer
- psychosocial
- survivorship
- caregivers India

Introduction

Pediatric cancer incidence in India has been on the rise and an increasing number of patients and families are affected.[1] However, data regarding childhood cancer is still prominently urban and restricted to certain sections of the population. While better outcomes are observed along with better access to health care, these strides are still comparatively modest.[1] Childhood cancer care services are mostly limited to major tertiary care centers in large cities and many patients and their families must travel, find accommodation, bear significant financial burden, and navigate the complex process of screening, diagnosis, and treatment related decision making with little to no support.[2]

Due to diagnosis in early infancy, childhood, and adolescence, pediatric cancer survivors face major concerns during and after treatment and for significant parts of their lives. Cancer survivorship as a domain has emerged for pediatric patients from the need to provide better quality of life (QoL) and predict and prevent late effects.[3] In a condition like cancer, survivorship has been historically focused on the policy-related or disease statistic-related aspect, but has expanded in the past two decades to include psychological,

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social, and physical concerns of cancer survivors, their QoL, and overall well-being.[3]

Pediatric Cancer Survivorship

Work in cancer survivorship has taken the form of research and clinical practices that endeavor to understand survivor challenges and deficits in physical, emotional, and social support. It delves into areas such as stress and mental health, physical activity, burden of illness, recurrence of cancer, communication, health care experiences, care coordination, working with caregivers of survivors, and more.[4,5] Pediatric cancer survivors are especially susceptible to physical and mental health concerns later in life and survivorship in pediatric cancer has been the focus of extensive research.[6] There is a requirement for long-term follow-up plans that deal with issues like transition of care, parent and family concerns, information and management of the health of the patient and posttreatment supportive care, and tackling concerns regarding recurrence of the disease.[3,7] Pediatric cancer survivorship is now treated as a lifelong process, with need for attention to survivor and family well-being in research and practice.[8]

With extensive cohort research[9] as well as qualitative research worldwide,[10–12] the scope of pediatric cancer survivorship now ranges from immediate logistic and physical concerns in recovery,[7] to longer term issues such as transition in care as the patient moves to adulthood.[11] There are more mental health-related studies, dealing with both distress and mental illness[13] as well as posttraumatic growth.[14] For caregivers, there is a variety of research that focuses on their own mental health and well-being, their distress, and information and care needs.[15,16]

In survivorship research, organ loss is discussed commonly in cases of breast, prostate, and uterine cancers.[17] In childhood cancer survivorship there is little to no discussion on how QoL may be impacted by organ loss or how the decision-making related to procedures that lead to organ loss can be. Little is known about the decision making around accepting treatment plans that may result in organ loss and ensuing complications or when treatment refusal can likely result in further spread of the cancer and loss of life.[18]

Treatment experiences, refusal, and abandonment are other areas that remain largely unexplored exclusively as parts of pediatric cancer survivorship. Refusal of follow-up medical care is common among pediatric cancer survivors especially when the original illness and its treatment may have been difficult and traumatizing to the child.[19] Treatment refusal is also closely related to psychosocial factors as well as education, economic, and cultural factors.[20,21] It is necessary to explore this area further as a part of psycho-oncological research.

Pediatric Psycho-Oncology

Pediatric psycho-oncology falls between psychiatry, psychology, and pediatric health care.[22] Cancer diagnoses during childhood are highly likely to impact both the child and their family and pediatric psycho-oncology attempts to understand their psychosocial, emotional, and supportive care needs while coping with this life-altering situation.[4] Over the past few decades, research in pediatric psycho-oncology has expanded to include communication and treatment-related information sharing and understanding parent and caregiver concerns.[3,22] Pediatric psycho-oncology today encourages the involvement of oncologists and other health care workers alongside psychologists and social workers to collaborate and develop systems that aim to maintain high standards of patient-focused and caregiver-focused care.[22] Pediatric oncologists are actively choosing to refer their patients and patient families to professionals to aid in mental health and supportive care needs and the unique importance of the role of the pediatric psycho-oncologist has been reiterated.[23]

Pediatric Psycho-Oncology Research in India

In high-income countries, attention to psychosocial aspects of health in pediatric cancer has become the standard for health care providers, with greater efforts to study and assess patient and caregiver needs with sound theoretical underpinnings.[24] This progress, however, is not reflected equally in lower- and middle-income countries and especially in India where the oncologist is usually the primary (and often times only) source of care offered, and the care is largely medical and surgical. Considering the nonstandardized nature of Indian healthcare systems, tremendous patient footfall, and limited number of tertiary care centers and specialists, this is an unavoidable deficit at present, but efforts toward more substantial research are observed.[25] Although neither as consistently nor richly as in the west, some studies have attempted to explore the needs and impact of pediatric psycho-oncology practice in India.[26,27]

The present narrative review aims to take an overarching view of psycho-oncological research in India in the past two decades and present key findings as well as examine the scope and major themes of these studies.

Methods

Online databases such as MEDLINE (though PubMed) and Google Scholar were searched using search terms “pediatric cancer,” “childhood cancer,” “survivorship,” “psychosocial,” “psycho-oncological,” and “India.” A manual search of journal articles and bibliographies of listed articles was also conducted for relevant studies. A total of 78 results were found which were then further sorted for relevance. The titles and abstracts of original articles were screened for research related to psycho-oncology and psychosocial aspects of pediatric cancer conducted in India and with Indian participants. A total of 31 articles were found to be relevant.

Inclusion: Original research studies conducted in India focused on (1) patients diagnosed with pediatric cancer, or (2) parents and caregiver of children with pediatric cancer, or (3) health care providers treating children diagnosed with pediatric cancer, or on all of the above.

Exclusion: (1) studies based on treatment protocols, screening, and intervention with no examination of psychosocial factors and (2) articles published prior to the year 2000.

Several articles published in this domain are systematic, narrative, and comparative reviews or expert commentaries (9) which were excluded since these articles present evidence and critique on the existing literature and are therefore secondary sources of literature. Studies where the full article was unavailable or studies that were cited from conference presentations and abstracts without publication (6) were excluded as well. A total of 16 articles were included in the final review.

Due to the large variations in methods of the studies, use of qualitative methods, and smaller sample sizes, a narrative review method was chosen instead of a systematic review or a meta-analysis. This enabled the highlighting and a greater understanding of the deficits in research in India. The selected articles were organized into themes that most effectively highlighted their findings and implications and provided an overarching view of the existing studies (►**Table 1**). Themes were chosen based on areas of research observed in the literature review and on the areas of focus as seen in overall research in pediatric psycho-oncology.

Results

Overview of the Research

A majority of the psycho-oncological studies conducted in India on pediatric cancer focuses either on survivors or parents and caregivers together. This ranges from understanding their experiences of diagnosis and treatment to QoL and the impact of health care services such as communication, dissemination of information, and supportive care.

The limited number of studies and dispersed focus of studies included in this review further illustrate the need for extensive and focused psycho-oncological research in pediatric cancer in India.

Patient, Parent, and healthcare Provider Communication

While knowing the child's diagnosis seemed to cause significant distress in parents,[28,29] awareness of treatment plans and their side effects also appear to be helpful; there is little clarity on how they are helpful. The studies detail shortcomings in the disease-related counseling provided by health care workers, which included a need for greater information regarding late effects on the child's growth and development.[28,29] Significantly, parents reported that they believed their child to be aware of their condition while they were completely reluctant to inform the child of their diagnosis.[28,29] However, if the patients (children) needed to be informed, parents relied heavily on the treating physician to do so but were also particularly invested in the timing and manner in which the information should have been provided to the child.[30,31] In palliative care especially, which was a sensitive topic for both patients and providers, the parents wished to shield their child from the prognosis and a majority believed strongly that care-related decisions should be left solely to them while fewer believed that only the physician or both parents and physicians should be involved in the decision making.[30,31]

For studies that involved disease counseling for mothers of children diagnosed with pediatric cancer,[28,29] most of the information delivered by the health care providers was considered satisfactory. The mothers were able to retrieve the information a few months afterwards and a majority were well aware of how their child's treatment would progress, possible side effects of the treatments, and a majority reported being worried and feeling anxious despite most of them being satisfied with the quality of care their child was receiving.[28,29] Across studies, the need for communication skills training and for improved patient-provider interaction was reported and discussed, the specifications for which, however, were not mentioned.

Patient Needs and Psychosocial Concerns

The most common patient concerns for those undergoing treatment pertained to navigating the decision making, actual process and treatment-related pain, and other side effects.[32,33] While these overtly appeared physical, they further extended to psychosocial concerns such as low mood, feeling anxious or helplessness, and overall worry about the patient's well-being among caregivers[32,33] The impact on education and activities of the patients were explored with most parents and caregivers reporting concern regarding the child being unable to complete activities or milestones that their peers would be, falling behind and have difficulty cultivating new social relationships and maintaining existing ones.[32,33]

Stigma was reported as a major concern, with parents and caregivers reporting that responses such as pity from others would cause the patients to lose self-confidence and it was difficult for them to address these issues with their friends to make play or activities more inclusive or suitable to the child's needs.[33] While fewer patients themselves reported distress,[33] parental perception of distress was greater.[32] Across studies, the need for informational support presented either directly[33] or indirectly (as concern over uncertainty of prognosis) as well as a distinct apprehension regarding relapse and subsequently responding to questions related to mortality by the patient.[32]

Psychosocial Interventions in Pediatric Cancer

Of the interventions provided in Indian settings, there are combined interventions with psychosocial objectives as the central objectives as well as combined with physiological outcomes,[34] with preliminary studies such as an intervention pilot[35] and a single-patient case study. All intervention studies present a common aim of improving overall functioning of the patients and their families. Involving allied professionals such as social workers[36] or clinical psychologists[35] appear to be preferred. However, the availability of these allied professionals is limited and the social workers primarily interact with the families of patients.[34] With individualized cases or child-parent dyad-based interventions, potential options toward introducing different types of therapy were explored, significant improvements were reported in the participants' activities and coping and a decrease in levels of posttraumatic stress.[35,36]

Table 1 Included articles (listed according to theme)

Theme	Author/s	Method	Participants	Focus
Communication in pediatric cancer	Seth.	Structured interviews	Parents of pediatric cancer patients	Barriers to communication and parental views on cultural communication
	Singh et al	Structured interviews	Parents of pediatric cancer patients	Barriers to communication in chemotherapy and palliative care
	Sen	Self-report questionnaires postdisease counseling	Parents of pediatric cancer patients	Exploration of parental understanding of their child's diagnosis and coping after disease counseling by physicians
	Nair et al	Self -report questionnaires postdisease counseling	Parents of pediatric cancer patients	Exploration of the parent's understanding, response, and attitude regarding their child's diagnosis after disease counseling offered by physician
Patient needs and psychosocial concerns	Gopalakrishnan et al	Mixed-methods (structured interview and pediatric distress thermometer)	Patients and their primary caregivers	Shift in medical care and resulting concerns in pediatric cancer patients during the COVID-19 pandemic, from caregivers' perspective
	Shunmugasundaram and Veeraiah	Semi-structured interviews	Caregivers of pediatric cancer patients	Exploratory research aimed at understanding psychosocial issues of pediatric patients with osteosarcoma
Psychosocial interventions in pediatric cancer	Kaushal et al	Randomized control pilot trial	Pediatric cancer patients and parents	Composite Intervention Module for Preadolescents with Acute Lymphoblastic Leukemia (CIMPALL)
	Chari et al	Case study	Pediatric cancer patients	Design and implementation of a play-therapy based intervention for a pediatric cancer patient. Examination of feasibility of intervention
	Nair et al	Case study	Pediatric cancer patients and families	Learnings from voluntary support including financial, medical, and psychological offered at a pediatric oncology department at a tertiary care center
Parent and caregiver needs	Rao et al	Survey research	Caregivers of pediatric patients	Survey research aimed toward intervention design highlighting needs of

(*Continued*)

Table 1 (*Continued*)

Theme	Author/s	Method	Participants	Focus
				caregivers including physical, emotional, logistic, and information and interest in support group
	Rajajee et al	Questionnaire-based survey	Parents of pediatric cancer patients	Assessing the effects of the cancer diagnosis on the family and coping mechanisms adopted by the family and variations based on family structure
Survivorship, outcomes, and quality of life	Jatia et al	Retrospective demographic analysis	Pediatric cancer survivors	Data of survivors from late effects clinic providing holistic supportive care
	Rajendranath et al	Cross-sectional survey	Pediatric cancer survivors	Assessment of quality of life and neurocognitive function for survivors to understand late effects
	Prasad et al	Retrospective demographic analysis	Pediatric cancer survivors	Data of survivors over three decades in a late-effects clinic analyzed for physical and psychosocial concerns and need for support
	Bansal et al	Comparative study	Pediatric cancer patients and their siblings and other healthy children	Comparing health-related quality of life of children with acute lymphoblastic leukemia (ALL) with their siblings and other healthy children
	Bansal et al	Cross-sectional survey	Parents of pediatric cancer patients on maintenance therapy	Parental perspectives on health-related quality of life assessment for children on maintenance therapy for children with acute lymphoblastic leukemia (ALL) and their siblings

Abbreviation: COVID-19, coronavirus disease 2019.

While the need for both child-centric interventions and holistic support ones have been highlighted, the outcomes are mainly focused on neurocognitive measures in children while psychosocial evaluation in parents was more common.[34,35] All interventions mentioned feasibility but only one had measures in place for feasibility assessment.[35]

Parent and Caregiver Needs

Studies focusing on psychosocial issues commonly found emotional concerns, awareness about managing the child's illness, and behavioral concerns in both the patients and their siblings.[37,38] Parents reported distressing emotions such as fear, anxiety, and increased need for support.[37] Most parents reported that family support was a crucial aspect in coping[38] and receiving support from relatives was a factor that impacted responses to psychological and financial stressors which increased due to additional responsibilities such as caring for other sick family members[37] and based on the parent's gender.[38] Mothers were reported bearing not just the emotional and psychological impact of the child's illness but also their aggressive and temperamental behaviors since they were most commonly the child's primary caregivers.[38] These shared concerns, therefore, pointed toward the benefits of forming and utilizing support structures in the form of support groups and group therapies.[37,38] There was a distinct differentiation in the needs faced; mothers emphasized on emotional distress and caregiving-related support deficits while fathers focused on logistical and financial needs, even though they did report initial emotional upheaval at the time of diagnosis.[38] However, despite reporting of parental concerns, help seeking was still comparatively low and most parents relied on familial support rather than seeking professional help.[37,38]

Survivorship, Late Effects, and Quality of Life

Health-related QoL was assessed with psychosocial factors being highlighted specifically alongside physical concerns. Survivors of childhood cancer typically appeared to have poorer QoL overall, both health-related, sociocultural, and personal.[39,40] Due to the most common assessments of QoL being closely clubbed together with health-related outcomes, neurocognitive and scholastic assessments were used commonly.[39,41] Use of intelligence scales primarily showed neurocognitive impairments in a sizeable number of patients assessed.[39,41] A significant number of patients reported these alongside scholastic problems that included absenteeism in school due to frequent health procedures and hospital admissions.[40] Dropping out of school was another concern and parents reported not only academic challenges but also social struggles with making friends and difficulties competing with peers.[40–42]

Other psychological concerns included emotional distress that required interventions by mental health professionals[39] as well as everyday problems such as sleep-related issues.[40,42] A majority of the survivors, when compared with their siblings and other healthy children, showed greater levels of anger and sadness as well, all of which combined with other physical health measures indicated that they had lower levels of health-related QoL than their healthy siblings or other healthy children.[40,42] However, interestingly the children with cancer (as reported by parents) faced greater bullying than their siblings but not as much as other healthy children.[40] This may be attributed to various reasons which were not explored in detail in the studies examined.

Finally, the importance of holistic support and follow-up was highlighted, with studies suggesting that regular follow-up and alongside psychosocial, financial, logistic, and educational support provision could reduce the numbers in treatment abandonment and treatment refusal.[43] There was great emphasis on follow-ups and assessments of survivors[41,43] and reported formation of structures such as support groups that provided psychosocial input and abandonment tracking that actively identified when patients missed follow-ups and alerted the health care professionals responsible for their care.[43]

Discussion

Pediatric psycho-oncology research in India has progressed with greater incentive from health care providers as well as increased access to tertiary care centers that are able to provide psychological support and intervention through allied professionals.[25] This progress, however, still appears to be scattered and focused in urban populations and heavily oriented toward survey-based research with detailed qualitative or intervention-based studies appearing few and far-between.[44]

Due to their age, pediatric cancer patients are often examined and assessed through the eyes of their family members, caregivers, and other healthcare providers.[29,40] These assessments are prone to human error and parental experiences of their child's cancer-related issues require greater exploration through diverse methodologies. Parental experiences require research separated from children's needs, with greater emphasis on gender-related, cultural, socioeconomic, and geographical differences being accounted for.

Patient-provider and parent-provider communication is severely underexplored with research often being replicated with little critical assessment of methodology.[30,31] The limited amount of research in this area is concerning, considering cultural and social heterogeneity in patients in India. The importance of information in pediatric cancer has been highlighted through multiple studies worldwide[45–47] and the needs of parents of children with cancer and its effect on treatment-related decision making and coping require detailed research, with clear methodological markers in Indian settings.

Surveys and focus groups examining parent and caregiver needs provide crucial data and illustrate caregiver coping with solution-oriented research that can help address the gap between supportive care, informational, financial, and logistical aspects of pediatric cancer care.[37,38] Existing studies, however, are largely survey- or questionnaire-based which are effective for greater number of participants but do not provide researchers adequate opportunity to understand the psychosocial underpinnings of these needs or the heterogeneity in these needs due to culture, gender, and regional differences.[37,38] While these studies illustrate that both family members require support and that the active involvement of health care providers in addressing these needs is necessary, greater research is required to understand the specificity of the needs. Considering the sheer patient volume in Indian clinical settings, the forays into intervention-based research are crucial and were conducted systematically with strong evidence-based frameworks that show potential for improved outcomes.[29,35,36] Peer support is documented as a highly viable tool for improved coping and studies that look at feasibility of support groups both for survivors and their parents and caregivers are crucial.

Psycho-oncological research in childhood cancers is predominantly focused on survivorship and late effects with a majority of the research being conducted in clinical settings and thus often clubbed together, part and parcel with studies assessing late effects or QoL as a whole,[28,30,31] with biomedical and physical aspects taking precedence or receiving greater attention than psychosocial ones. These studies are most commonly conducted through clinical settings such as tertiary care pediatric oncology departments and outpatient facilities.[31,40] Using a cross-sectional survey design appears to be a preferred method followed closely by retrospective data analyses of patients who have or sought or are seeking treatment at the facility.

Survivorship research is also often heavily focused on health-related QoL that involves overall health-related functioning and physical late effects but make generalized mention of psychosocial problems with little focus on specific psychological stressors such as relational issues, self-esteem, or other concerns specific to the individual survivor, which are paramount in effective coping for survivors.[13,22] Little is known about supportive care needs for survivors after they have transitioned to adulthood and the impact of leaving regular pediatric health care. Pediatric cancer survivors are far more likely to face psychosocial complications alongside further health anxieties and there is a need to explore these dynamics.[12,45] Critical concerns like organ loss or loss of functionality in organs in pediatric cancers can be a life-altering event affecting the lives of both survivors and their family.[46] Bereavement counseling may be operational in end-of-life care but literature shows no evidence of it being employed in cases of organ loss.[47] With only a handful of studies being specific to the type of cancer being studied, unique concerns may not be highlighted and assessment of condition-specific issues cannot be undertaken.[31,40]

With progress in pediatric psycho-oncology research worldwide being accelerated to ensure greater standards of care for patients, caregivers, and the active involvement of health care providers in forms of multiexpert teams,[24,25] Indian research will be required to make robust strides with methodologically sound research rooted in strong theoretical frameworks.

Limitation

Due to the structure of narrative reviews, there is little focus on methodological aspects in the examination of existing literature. The present review also presents a brief overview with a limited number of studies included based on availability, lack of access to full articles, and time constraints.

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Conflict of Interest

None declared.

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When Do Patients with Breast Cancer Seek Help from Psycho-oncology Services? A 3-Year Retrospective Study from India

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Abstract

Introduction Breast cancer is the most frequent cancer among women. In the last few decades, the outcome of breast cancer has improved significantly in terms of survivorship and quality of life. However, it is crucial that alongside managing the disease, breast cancer services address and manage associated or co-occurring psychiatric illnesses such as acute stress reactions, procedural anxieties, adjustment issues, depression, and fear of recurrence, which leads to an overall better experience of the patient.

Objective There is a paucity of data on the patterns of psychiatric morbidity in patients with breast cancer who access psycho-oncology services in a naturalistic setup outside research studies from India. The current study focused on exploring this alongside reporting the common treatment methods adopted for this group of patients.

Materials and Methods Real-life data from electronic patient records were retrospectively reviewed for all patients with breast cancer accessing integrated psycho-oncology services in a tertiary care hospital in India over three 3 years (2018–2020). The various psychiatric morbidities were reported, along with associated cancer demographic data, disease characteristics, and treatment details.

Results Of all the breast cancer patients ($n = 338$) in the calendar years 2018 to 2020 reviewed by psycho-oncology services, the most common psychiatric diagnosis was depressive illness ($n = 100$, 29.6%), followed by adjustment disorders ($n = 68$, 20.1%) and anxiety ($n = 66$, 19.5%). There was a significant minority with serious enduring mental illnesses such as schizophrenia ($n = 11$, 3.3%) and bipolar disorders ($n = 14$, 4.1%). On the other hand, 14.2% ($n = 48$) of the patients with breast cancer who attended Psycho-oncology outpatient department did not have any psychiatric syndrome. Around 16.3% of patients could be managed without a prescription for any medications and almost half of the patients needed only one psychotropic medicine. Psychological interventions were used for 45.6% of patients.

Keywords
- breast cancer
- India
- medical oncology
- psychiatry
- psycho-oncology
- psycho-oncology service

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Conclusion Integrated psycho-oncology services in a cancer hospital catering to patients with breast cancer help in psychiatric assessment, diagnosis, and addressing the mental health needs of patients. The treatment offered needs to be nuanced and individualized and may require a combination of psychotropic medications and psychological techniques.

Introduction

Breast cancer is presently the most diagnosed cancer and the fifth leading cause of death worldwide.[1] In India, it is the most frequent cancer among women.[2] In the past three decades, remarkable advancements have been made in breast cancer treatments, especially in the areas of surgery, radiotherapy, targeted systemic therapies, genomics, and molecular biology that in turn has not only improved overall survival (including disease-free survival) but has also resulted in better management of the axilla, more acceptable cosmetic outcomes, and reduced treatment time and hospital visits.[3] Due to enhanced survivorship and better cosmesis, patients often face minimization of the subjective distress associated with the diagnosis. They often face comments as "it's only breast cancer" and that "there is nothing much to worry about."[4] However, objective data show, despite the medical advances, rates of psychological morbidities is highest among patients with breast cancer as compared to all other cancers.[5] Breast cancer treatments, although ensuring longer survivorship, affect nearly all the key aspects of femininity including sexuality, physical identity, fertility, and the ability to breastfeed.[4] The diagnosed person or the survivor deals with a plethora of issues including a constant preoccupation about the relapse of cancer, body-image issues related to mastectomy, lymphoedema and hair loss, anticipated problems in companionship, sexual intimacy, reproduction, and parenting abilities, and even worries about passing the "cancer gene" to their grown-up children.[3,6,7] Many of these concerns can be chronic and patients may continue to have anxiety and depressive symptoms for years.[8,9] These symptoms are often colored by the patient's perception of the disease, their illness experience, and the coping resources of the person. Interestingly studies showed that the psychological symptoms are not associated with any biological prognostic factors like tumor size, histology, number of axillary lymph nodes involved, or other treatment-related factors, except for adjuvant chemotherapy which has been found to increase the risk for either or both anxiety and depression.[8] The patient's concerns have a significant impact on the family members. The prevalence of anxiety and depression in family/caregivers is similar to that of breast cancer patients.[10] In India, caregiving is mostly performed by family members (both physical and psychological) and in most cases, family members do not feel the need or have the means to seek professional help.[11] Family caregivers of cancer patients often report significant anxiety or depressive symptoms and these symptoms persist during the initial months and years following the cancer diagnosis.[12] Therefore, there has been an increasing emphasis on the psychosocial care of breast cancer patients, survivors, and caregivers. A recent study conducted in India points out that both the patient and the caregiver seek structured counselling services for patient–caregiver dyads, improved doctor–caregiver communication, and routine practice of disclosure of cancer diagnosis.[13]

Psycho-oncology is a relatively recent area of specialization in India and not many cancer centers in India have a psycho-oncology service accessible to patients, although this is changing rapidly. One paper cites the lack of routine integration of psychosocial care in cancer settings.[14] Most psycho-oncology studies conducted in India usually point to the need for the development of psychosocial approaches for cancer that are suitable and acceptable to patients. In this article, we report the types of mental health issues faced by patients with breast cancer who were assessed by the psycho-oncology unit in a tertiary cancer hospital in eastern India over 3 years starting from January 2018 and ending in December 2020. The article also discusses a service delivery model that is suited to low- and middle-income country settings.

Objectives

The main objective of the current study was to explore and describe the nature of psycho-oncological services accessed by patients with breast cancer in a specialist cancer center.

Materials and Methods

Study Design

The study follows a design of a retrospective case series for a period of 3 years based on a contemporaneous electronic medical record of psychiatric assessments documented for all the patients by the treating consultant psychiatrist after ethical clearance for the institutional review board.

Setting

This study was conducted in a tertiary, philanthropic cancer care center serving eastern Indian states and neighboring South Asian countries like Bangladesh, Nepal, and Bhutan. Currently, the hospital has a capacity of 431 beds and caters to a large catchment area.

Psycho-oncology Services

The study hospital has a well-functioning psycho-oncology service, developed since the very beginning of the hospital's inception and currently maintained by two consultant psychiatrists and clinical psychologists. The department has daily outpatient and in-patient services and works consistently and routinely for patients reaching out for psychological aid. The hospital's breast disease management protocol ensures optimal access for patients, who at times come with ailments in the context of their cancer diagnoses and at other times with a premorbid psychiatric illness that might affect cancer treatment itself.

Duration of Service Assessed

The duration of the study was for three calendar years, from January 1, 2018 to December 31, 2020.

Collection of Data

The study hospital maintains an electronic health record system and the department of psycho-oncology maintained contemporaneous health records electronically. Data were collected from the existing health records. The electronic hospital management system provided the demographic and clinical data for the patient and was supplemented by manual documents of the hospital. Institutional ethics approval was obtained (EC/WV/TMC/49/20) for the study.

Analysis of Data

All breast cancer patients who were assessed by the psycho-oncology department between 2018 to 2020 were included in the study. Simple descriptive statistics were used with frequencies to describe the patients accessing psycho-oncology services. The continuous variables (age and distance of the patient's home to the hospital) were checked for normality with the Shapiro–Wilk test and Q–Q plots and an appropriate measure of central tendency was used to describe the data. Since the results suggested that our data were not normally distributed, we proceeded to use the median and the interquartile range as descriptive parameters for the data.

Ethics

The present study was in accordance with the ethical standards of the institutional ethical committee, national guidance on research ethics, and the 1964 Helsinki Declaration and its later amendments.[15] The study was approved by the institutional ethics committee of Tata Medical Center, Kolkata. In view of the retrospective nature of the study, a waiver of consent was obtained from the institutional ethics committee of Tata Medical Center, Kolkata. As per institutional policy (IEC Protocol Waiver No – EC/WV/TMC/49/20 on August 18, 2020).

Results

A total of 2,448 patients were treated by the breast onco-surgery team between the years 2018 and 2020, out of which 338 patients reached out for psycho-oncology services (►**Table 1**). Of 338 patients, 335 were females, while three of the patients were adult males with breast cancer. The age of the patient and the distance of the patient's home to the hospital were both continuous variables that were not normally distributed. The age of patients ranged from

Table 1 Description of the data/sociodemographic details

Variable		*n* = 338	%
Age (in years) at presentation		**Median = 48.50 (IQR: 41–57)** **Maximum = 76** **Minimum = 23**	
Gender	Female	335	99.1
	Male	3	0.9
Marital status	Married	307	90.8
	Single	21	6.2
	Widow	10	3
Fund	Yes	47	13.9
	No	291	86.1
Occupation	Homemaker	286	84.6
	Business	4	1.2
	Government job	16	4.7
	Private job	6	1.8
	Other	22	6.5
	Retired	4	1.2
Distance (in kilometers)		Median = 56.30 (IQR: 20.20–229.48) Maximum = 1,583 Minimum = 1	

Abbreviation: IQR, interquartile range.

23 years to 76 years with a median age of 48.5 years (interquartile range [IQR]: 41–57). They were mostly homemakers ($n = 286$, 84.6%), followed by government employees ($n = 16$, 4.7%). Four patients ran personal businesses ($n = 4$, 1.2%). The median distance between the hospital and their home was 56.3 km (IQR = 20.2–229.48 km) with the longest distance travelled by any patient being 1,583 km.

Of the 338 patients who accessed our service, 319 patients (94.4%) had a diagnosis of invasive ductal carcinoma, whereas 9 patients (2.7%) had invasive lobular carcinoma. Other carcinoma types (3% of all patients) included ductal carcinoma in situ, invasive mammary carcinoma, and carcinomas of no special type/mixed type (►**Table 2**). Among the patients who accessed psycho-oncology outpatient department, 171 (50.6%) patients were at stage 2 cancer, 110 (32.5%) patients had stage 3 cancer, and 45 (13.3%) patients were diagnosed to have stage 4 cancer. More than half of the patients (51.5%) patients underwent mastectomy, while 34.9% of patients underwent breast-conserving surgery. Among all the patients, 13.6% patients did not undergo any form of surgery as they had distant metastasis. Almost three-fourths of the patients (73.4%) did not have any distant metastasis. Most (88.8%) patients underwent some form of chemotherapy. More than three-fourths of all patients (83.1%) were given radiation therapy, while two-thirds of the patients (66.9%) received hormone therapy. More than half of all patients (190 or 56.20%) presented with some form of medical comorbidity; of them, 59 (17.45%) patients had at least two comorbidities and 26 (7.69%) had more than two comorbidities. Hypertension was the most common comorbidity reported in 123 (64.73%) patients, followed by diabetes in 68 (35.78%) patients and hypothyroidism/hyperthyroidism in 55 (28.94%) patients. Only 35 patients (10.35%) had both diabetes with hypertension.

Of all the breast cancer patients reviewed by psycho-oncology services, the most common psychiatric diagnosis was depressive illness ($n = 100$, 29.6%), followed by adjustment disorders ($n = 68$, 20.1%) and anxiety ($n = 66$, 19.5%); next were major psychiatric disorders such as schizophrenia ($n = 11$, 3.3%), bipolar disorders ($n = 14$, 4.1%), organic mood or psychotic disorders ($n = 9$, 2.7%), and neuro-cognitive disorders ($n = 3$, 0.9%) (►**Table 3**). Amongst the patients who were referred, 14.2% ($n = 48$) of the breast cancer patients did not have any psychiatric syndrome. There was no report of completed suicide amongst the patients diagnosed with breast cancer in the year for which the data were being analyzed. The number of treatment contacts with psycho-oncology services varied and ranged from a single contact to 24 separate contacts with mental health professionals, the median number of contacts being 2 (IQR = 1–4). The number of contacts was more (median 3.50, IQR = 1.75–9.25) for people with known severe enduring mental illness. Based on the median score, the entire sample of patients included in the study was divided into two groups (1–3 evaluations vs. >3 evaluations by psycho-oncology). The chi-square test was used for exploring the association of those with and without severe mental illnesses (e.g., schizophrenia, bipolar disorder, etc.), the total number of evaluations by psycho-oncology (1–3 evaluations vs. >3 evaluations by psycho-oncology) was found to be statistically significant ($p < 0.01$). While some of the patients evaluated (16.3%) did not need any psychotropic medications, almost half of the patients (48.52%) were managed with only one medication for their symptoms. An almost equal percentage of patients (45.6%) also needed psychological interventions in the form of psychoeducation, psychological support, coping strategies, suggestion for lifestyle modifications including sleep hygiene techniques, or a combination of these.

Discussion

Studies in various parts of the world suggest that patients require individualized treatment plans according to their needs.[16–18] In the current article, around half of the patients who accessed psycho-oncology services presented in advanced stages (stage 3 or 4), while others presented in earlier stages. The majority of the patients received curative surgery, radiation therapy, and/or chemotherapy based on the weekly multidisciplinary group discussions. The common reasons for referral to psycho-oncology from the perspective of the oncologist were low mood, fragmented sleep, restlessness, and being agitated or expressing suicidal thoughts. It was rare that a syndromic psychiatric diagnosis was mentioned in the referral. Of the patients who were referred, most were diagnosed with depressive disorder ($n = 100$, 29.6%), followed by adjustment disorders ($n = 68$, 20.1%) and anxiety disorders ($n = 66$, 19.5%). European and American guidelines stress the need for the incorporation of psychological interventions in breast cancer services.[19,20] Even with significant improvement in the outcome of breast cancer over the last few decades, a survey conducted in 32 countries in Europe showed that only one-third of the countries had documented requirements and specific indicators for psychosocial interventions, resources they require, and educational requirements.[19] The role of psychosocial support remains crucial in treatment. "The SARS-CoV-2 pandemic had affected cancer care and service delivery around the world and we published the impact of the pandemic on psycho-oncology services separately."[21]

A recent review[22] covering several studies around the globe, including India, concluded the prevalence of depression in breast cancer to be around 32%. The higher rates of psychiatric morbidity reported in this audit were perhaps because we only evaluated patients who were referred. All patients are assessed by the breast surgery or medical oncology teams and referred to psycho-oncology as per accepted disease management guidelines when suspected to have psychological or psychiatric morbidity. Some patients diagnosed with syndromic psychiatric morbidity needed pharmacological management. Depression in breast cancer is associated with increased morbidity, suicidality, and longer hospital stays for treatment.[23] Depression can result in poorer adherence to cancer-specific treatments[24] and that may indirectly increase the risk for mortality. Antidepressants including selective-serotonin reuptake inhibitors are recommended for managing syndromic depression and these are effective in this group of patients.[25]

Table 2 Cancer disease characteristics of our sample group

Variable		$n = 338$	%
Type of cancer	Invasive ductal carcinoma	319	94.4
	Invasive lobular Carcinoma	9	2.7
	Other	10	3.0
Stage of breast cancer	0	3	0.9
	1	9	2.7
	2	171	50.6
	3	110	32.5
	4	45	13.3
Estrogen receptor status	Positive	218	64.5
	Negative	120	35.5
Progesterone receptor status	Positive	191	56.5
	Negative	147	43.5
HER2 receptor status	Positive	79	23.4
	Negative	233	68.9
	Equivocal	26	7.7
Type of surgery	Breast-conserving surgery	118	34.9
	Mastectomy	174	51.5
	None	46	13.6
Chemotherapy	Yes	300	88.8
	No	38	11.2
Radiotherapy	Yes	281	83.1
	No	57	16.9
Trastuzumab therapy	Yes	44	13.0
	No	294	87.0
Hormone therapy	Yes	226	66.9
	No	112	33.1
Metastasis	Yes	90	26.6
	No	248	73.4
Brain metastasis	Yes	20	5.9
	No	318	94.1
Number of comorbidities	No comorbidities	148	43.8
	Comorbidities	190	56.20
	1	105	31.06
	2	59	17.45
	>2	26	7.69
Comorbidity types	Diabetes	68	35.78
	Hypertension	123	64.73
	Diabetes and hypertension	35	10.35
	Hypo/hyperthyroidism	55	28.94
	Electrolyte imbalance	2	1.05
	Sepsis	1	0.52
	COPD	5	2.63
	Others	47	24.73

Abbreviations: COPD, chronic obstructive pulmonary disease; HER2, human epidermal growth factor receptor 2.

Table 3 Psycho-oncology factors and services

Variable		$n = 338$	%
Psychiatric diagnosis given	No psychiatric diagnosis	48	14.2
	Delirium	8	2.4
	Adjustment disorder	68	20.1
	Depressive disorder	100	29.6
	Anxiety disorder	66	19.5
	Substance abuse	1	0.3
	Schizophrenia	11	3.3
	BPAD	14	4.1
	Other psychotic disorder	5	1.5
	Organic mood and psychotic disorder	9	2.7
	Dementia	3	0.9
Number of medications	No psychotropic medication	55	16.3
	Prescribed medications	283	83.7
	1	164	48.52
	2	99	29.28
	>2	20	5.90
Type of medication	Sedative	93	32.86
	Antidepressant	210	74.20
	Mood stabilizer	26	9.18
	Antipsychotics	66	23.32
	Others	27	9.54
Psychological intervention	Yes	154	45.6
	No	184	54.4
Number of visits	All patients ($n = 338$)	Median = 2 (IQR: 1–4) Maximum = 24 Minimum = 1	
	SMD ($n = 30$)	Median = 3.50 (IQR: 1.75–9.25) Maximum = 15 Minimum = 1	
Previous psychiatric diagnosis (past history)	Yes	113	33.4
	No	225	66.6
Family history of psychiatric diagnosis	Yes	44	13.0
	No	294	87.0

Abbreviations: BPAD, bipolar affective disorder; IQR, interquartile range; SMD, severe mental disorder.
Note: Severe mental disorders (schizophrenia, BPAD, other psychotic disorders).

The majority of patients treated by us were managed with a single psychotropic combined with psychological interventions. Only around one-third of the assessed patients needed more than one psychotropic medication. This was mostly due to the use of nonsedative antidepressants like Venlafaxine, with less propensity to interfere with the metabolism of Tamoxifen,[26] but occasionally requiring additional short-term low-dose benzodiazepines for fragmented sleep. Overall, avoiding polypharmacy is recommended.

Psychological interventions were initiated for almost half of the patients seeking help, which is often the preferred mode of intervention for the management of issues related to coping with a cancer diagnosis and related predicaments like procedural anxiety, body-image issues, fear of recurrence, and psychological distress at the end of life. Psycho-education about possible symptoms, treatment needed, and behavioral and lifestyle interventions such as sleep hygiene were used frequently. Lifestyle interventions empower the patient and their relatives to initiate simple changes that may help them navigate through complex treatment processes when the psychological distress is transient.[27,28] Psycho-educational approaches, on the other hand, attempt to address realistic concerns by instilling a sense of control within transiently distressed patients; people with more serious psychological issues may need more specific psychological interventions.[29] As evident from our data, psychological interventions are brief as many patients accessed the service for a few sessions only. The people who came for repeated consultations usually had a pre-existing mental illness. The study emphasizes the need for an integrated psycho-oncology service model. This can improve access to mental health care in resource-poor low and middle-income countries like India.[30,31]

The typical referrals of patients with breast cancer patients managed by psycho-oncology services are represented in ►**Table 4**.

Service delivery model for psycho-oncology services for women with breast cancer in low- and middle-income countries:

Therefore, an integrated hospital-based psycho-oncology service for patients with cancer is proposed. It is necessary that clinicians treating women with breast cancer are initially sensitized about the magnitude of the problems and made aware of early warning signs of mental health difficulties that warrant a referral. The institutional breast cancer

Table 4 Typical presentation and psycho-oncology management of patients with breast cancer

Demographic and clinical profile	Psychological issues	Usual reason for referral and treatment goals	Interventions offered by psycho-oncology services
40–65-year-old lady, recently diagnosed with breast cancer, presenting with episodes of palpitation, breathlessness, feelings of impending doom whenever entering the hospital or day-care to receive chemotherapy.	Adjustment disorder with panic attacks	Reason: difficulty to accept the diagnosis, distress Goal: assist in adaptation	Psychological intervention addressing anticipatory anxiety, catastrophization and coping. If required, antidepressants with or without (for a short duration) benzodiazepines
40–60-year-old lady with breast cancer undergoing adjuvant chemotherapy and awaiting surgery with worries about the side effects of chemotherapy, surgery, outcome, and implication on her family especially children	Anxiety	Reason: anxiety about cancer and predicaments Goal: address anxiety and improve coping	Psychological intervention to address anxiety, relaxation techniques, psychological support If required, add antidepressants like Citalopram, Venlafaxine
45–65-year-old lady postsurgery for breast cancer with low mood, crying spells, terminal insomnia, diurnal variation of mood, anhedonia, decreased appetite	Depression	Reason: depressed mood, decreased motivation for treatment, suicidal risk Goal: assessment of depressive cognition and risk of suicide	Pharmacological (SSRI/TCA) and nonpharmacological intervention (cognitive behavioral techniques) for depression. Suicidal risk assessment and management
30–50-year-old lady postsurgery, postchemotherapy being upset with mastectomy and hair loss, presenting with interpersonal issues with her husband along with a feeling of estrangement in marital relationship	Body-image issues, marital discord	Reason: feelings of loss of physical identity, social stigma, and marital disharmony Goal: address body image concerns, empowering her, and improving communication within the marital dyad	Psychological interventions addressing body image and sexuality-related concerns, helping the partners to express their feelings and distress about cancer and the relationship, encourage dyadic coping
25–40-year-old married lady with living daughter presenting with known HBOC (hereditary breast and ovarian cancer) and anxiety related to need for ovary removal early in life, implication on perceived femininity, the implication of hereditary cancer on her daughter and unmarried cousins	Anxiety in the context of hereditary cancer	Reason: worries about risk reduction surgery; worries about passing the gene to offspring and social implication Goal: psycho-education, psychological support	Psychological support with validation of her concerns, allowing her to evaluate the pros and cons of the diagnosis, the chance of prevention of early cancer-related fatality in her and multiple family members by screening or risk-reducing surgery
50–70-year-old lady with metastatic breast cancer, currently undergoing end-of-life care under the department of palliative medicine, presents with being tearful, expressing remorse about multiple decisions she took in her life, with fragmented sleep.	Anticipatory grief	Reason: low mood, being upset since their transition from curative to palliative Goal: providing support	Pharmacological intervention for adequate control of physical symptoms like pain, and fragmented sleep. Psychological intervention to address the feeling of devastation, anticipatory grief, and abandonment. Arrange a meeting with close ones, helping to sort out things that she finds important, helping to find meaning and peace.
20–60-year-old family member of index breast cancer patient presenting with worries, low mood, and fragmented sleep since index patient received the diagnosis of cancer	Anxiety and depressive reaction in relatives	Reason: anxiety about treatment outcome, implication on family, relationship Goal: address anxiety and help to cope	Psychological intervention for anxiety, encouraging lifestyle modification, sleep hygiene, providing support. If required, add antidepressants like Mirtazapine, SSRIs

Abbreviations: SSRI, selective-serotonin reuptake inhibitor; TCA, tricyclic antidepressant.

treatment protocol practiced included specific pointers for such a referral. The psycho-oncology services are offered for both out-patients and hospitalized patients and are almost always started on the day of referral. The psycho-oncology team used pharmacological and nonpharmacological methods of treatments delivered by consultant psychiatrists and clinical psychologists. The typical patient profiles and interventions offered are discussed in ►**Table 4**.

Strengths and Limitations

All patients were reviewed by consultant psychiatrists as per the International Classification of Diseases 10 Revision. The psycho-oncology services were provided in the same hospital, available every day of the week, and most patients are seen on the same day of the referral whenever possible. The nature of the services was comprehensive for both outpatients and inpatients. Despite being a single-center study, this center caters to a wide geographical region in India and surrounding countries, and thus provides a large catchment area. Additionally, the robust electronic hospital management system resulted in thorough and consistent patient records. This emphasizes the role of an integrated service model in low- and middle-income countries.

The article presented data on those women with breast cancer who accessed psycho-oncology services. This article cannot comment on the patients with breast cancer who did not attend psychiatry consultations or the overall prevalence of psychiatric morbidity in women with breast cancer. The data are presented using simple descriptive statistics and further associations were not presented as the study was originally not powered for multiple testing and there were no a priori hypotheses. Also, for some patients, the stage of cancer progressed over time. Hence testing for associations was avoided.

Conclusion

This study showed that a significant number of women with breast cancer access psycho-oncology services, of whom around half of the patients had anxiety or depressive illnesses, one-fifth had stress-related adjustment disorders and only a minority (10%) had major psychiatric disorders like schizophrenia or bipolar affective disorder. The availability of integrated psycho-oncology services in the cancer center improved the access to mental health care for patients who wanted to seek help. This article attempts to highlight the importance and need for a psycho-oncology service model managing common psychiatric comorbidities in the present health care milieu.

Statement: all authors have participated in the write up of the article and approved the submitted version of the manuscript. All the authors fulfil the authorship criteria and declare that the manuscript represents honest work. The contents of this manuscript have not been copyrighted or published previously and are not under consideration for publication elsewhere. In addition, this manuscript will not be copyrighted, submitted, or published elsewhere while acceptance by "Indian Journal of Medical and Paediatric Oncology" is under consideration.

Conflict of Interest
None declared.

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Effectiveness of Structured Exercise Intervention in Cancer-Related Fatigue among Oral Cavity Cancer Patients: Randomized Controlled Trial

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Abstract

Introduction In head and neck cancer (HNC) patients, fatigue is present throughout the course of treatment and during follow-up. Cancer-related fatigue (CRF) is a significant treatment-related side effect experienced by oral cancer patients during and after treatment. CRF, when coupled with other side effects of oral cavity cancer, patients who undergo definitive treatment have some of the most dramatic acute side effects, and reduced overall quality of life (QoL). Although there are upcoming intervention strategies to manage CRF, the effect of exercise intervention is explored in this study. The rationale for considering exercise to manage CRF is that it may alleviate the combined effect of toxic treatment and decreased levels of activity during the treatment that reduces the capacity for physical performance.

Objective This study was conducted to investigate the effectiveness of exercise intervention on CRF, and its influence on functional capacity and QoL among patients with oral cavity cancer during and after their primary cancer treatment.

Materials and Methods Oral cavity cancer patients ($n = 223$), planned for only chemoradiotherapy with curative intent were screened for CRF. Based on the inclusion criteria, 69 patients were grouped randomly into experimental ($n = 35$) and control ($n = 34$) groups. Patients in the experimental group were provided structured exercise intervention, while the control group was offered standard and routine care. Structured exercise in this present study comprised moderate-intensity walking and resistance exercises using TheraBand every day for three to five times a week. CRF was assessed using symbolic assessment of fatigue extent and the functional capacity was assessed by 6-minute walk test (6MWT), maximal oxygen uptake (VO_{2max}), and hand dynamometer. QoL was assessed using the European Organization for Research and Treatment for Cancer-QoL (EORTC QLQ-C30) and the Head and Neck

Keywords
- cancer rehabilitation
- cancer-related fatigue
- exercise intervention
- functional capacity
- oral cavity cancer
- quality of life

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Cancer module (HN35), while distress was assessed by the National Comprehensive Cancer Network (NCCN) Distress Thermometer. Randomized patients were assessed at four points.

Result The size effects in fatigue extent ($\eta_p{}^2 = 0.40$) and fatigue impact ($\eta_p{}^2 = 0.41$) were found to be moderate, and a positive correlation between 6MWT, fatigue extent, and fatigue impact was observed.

Conclusion This study suggests that exercise intervention has a significant positive impact on CRF, most aspects of QoL, and the functional capacity of the patients.

Introduction

Oral cancer is the second most common cancer in India, accounting for 10.3% of the newly diagnosed cases in 2020.[1] In head and neck cancer (HNC) patients, fatigue is reported throughout the course of treatment and during follow-up.[2] Cancer-related fatigue (CRF) is a significant treatment-related side effect experienced by oral cancer patients during and after treatment. Patients frequently report CRF during and after chemotherapy or radiotherapy, the degree of which varies with the type of cancer.[3] As defined by the National Comprehensive Cancer Network (NCCN), CRF is a “distressing, persistent, subjective sense of physical, emotional and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning.”[4] In contrast to fatigue of daily life, weariness, or exhaustion from labor, exertion, or stress, which are usually relieved by rest, CRF is related to the disease prognosis or its treatments and will not be alleviated by rest.[5] CRF also affects cancer treatment. It may compromise the timing or completion of treatment regimens, either because fatigue has a dose-limiting adverse effect or because it reduces the patient’s willingness to adhere to the treatment regimen.[6] Prevalence studies with sample sizes above 1,000 reported CRF ranging from 14 to 66%[7] and a prospective Indian study on CRF among mixed cancer patients (45.6% HNC) reported that 84.5% had mild to moderate CRF and 3.3% had severe CRF.[8] A significant number of patients report CRF at the time of diagnosis and this number increases over the course of the treatment and lasts up to 3 to 4 weeks posttreatment. Concurrent treatment increases risk of developing or aggravating CRF.[3,8] HNC patients who undergo definitive treatment have some of the most dramatic acute side effects, which include, but are not limited to, severe mucositis, epidermal ulceration/desquamation of the neck, xerostomia, ageusia, and odynophagia, and when CRF is coupled with other side effects, it can be debilitating and lead to improper self-care, distress, malnutrition, loss of weight, productivity, and reduced overall quality of life (QoL).[9,10]

The NCCN-developed treatment guidelines for CRF recommend a moderate exercise training program to improve functional capacity and activity tolerance.[4] Many exercise programs for CRF are confined to 10 to 12 weeks of either aerobic or nonaerobic exercises.[11,12] However, the combination of home-based aerobic (walking) and anaerobic (resistance/therapeutic bands) exercises for cancer patients undergoing treatment is considered safe and executable, with greater adherence and positive influence on CRF and QoL.[13] The majority of the studies on exercise as an intervention on CRF were conducted among breast and prostate cancer patients, and few studies focused on other sites.[7] Clearly, knowledge of a patient’s CRF status before treatment onset and, ideally, during treatment is critical for an accurate understanding of posttreatment CRF. Hence, this study aimed to establish the effectiveness of exercise as an intervention on CRF among oral cavity cancer during their cancer therapy.

Objective

The objective of the study was to investigate the effectiveness of exercise intervention on CRF, and its influence on functional capacity and QoL among patients with oral cavity cancer during and after their primary cancer treatment.

Materials and Methods

Design, Setting, and Participants

This study adopted a randomized controlled trial comparing structured exercise intervention with standard cancer care. The approval for the project was submitted to the Cancer Institute Ethical Committee. This study followed the principles of the Declaration of Helsinki and was approved by the ethical committee meeting dated February 13, 2013. The study was conducted at the Regional Cancer Centre Chennai on histopathologically confirmed oral cavity cancer patients registered between June 2015 and November 2016. The HNC patients registered during the study period were enlisted. Among the HNC patients, those indexed having oral cavity cancer were chosen. The selected patients were screened for CRF using the symbolic assessment of fatigue extent (SAFE).[14] Severe CRF patients were not included in the study. Patients aged between 18 and 65 years, between stages I and IVA, planned for chemoradiotherapy (CRT) with curative intent as per the decision of the multidisciplinary tumor board, and with a performance status between 0 and 2 based on the Eastern Cooperative Oncology Group (ECOG) were considered eligible for the study. Only patients with mild and moderate CRF were selected purposively for the main study for random assignment into control and experimental groups for a structured exercise intervention. Patients with secondary cancer, severe CRF, and any physical comorbidity that would impair aerobic capacity or the ability to engage in physical activity, including diseases of the cardiovascular, pulmonary, neurological, metabolic, or musculoskeletal systems, and with nutritional deficiency (serum albumin <3.0 g/dL), or anemia (Hb <10 g) were excluded from the study. The medical records were used to screen the patients for the comorbidities, and the treating oncologists were also consulted for their fitness to take part in the study.

All the patients meeting the inclusion criteria were approached in the outpatient department and briefed about the study. Informed written consent was obtained from the patients to screen for CRF and to access their medical records and, if chosen, to participate in the structured exercise intervention. Following the screening, patients were randomized to prevent selection bias, and computer-generated random numbers were used for simple randomization of patients into control and experimental groups, with the help of a statistician. While the patients in the experimental group were provided structured exercise intervention, the control group was offered standard and routine cancer care.

Structured Exercise Intervention

The structured exercise intervention in this study focused on flexibility, muscle strength, and endurance, with an emphasis on strengthening proximal muscle groups and improving functional ability. All structured exercises were reviewed by the cancer rehab core team and followed the American College of Sports Medicine's (2000) general guidelines for exercise testing and prescription. The structured exercise in this study comprised moderate-intensity walking and resistance exercises using TheraBand.

Moderate-intensity walking (aerobic): Patients were advised to walk at their own pace for 20 minutes with mandatory 2 minutes of warm up with alternating cool down, three to five times in a week.

Minimal to moderate resistance exercise with TheraBand, grade 2 (anaerobic): Resistance exercise using TheraBand (grade 2) was structured based on prudent exercise guidelines. This comprised five sets of exercise that were structured for major muscle group of the upper limb: lateral raise, dynamic hug, chest press, reverse flies, and lateral pulldown.

The intensity of the structured exercise is guided by the Borg exertion scale for rating of perceived exertion (11–13/20 RPE). In the present study, patients were advised to do any three sets of exercise for 15 to 20 minutes in a day three to five times in a week. TheraBand (grade 2) and handout on exercise protocol and exercise adherence calendar were provided to the patients and the exercise was demonstrated to individual patients based on the protocol developed. The adherence to exercise was validated by the ward nurse during hospitalization and caregivers at home, using an adherence chart, and by the researcher over telephone, twice a week.

All the patients enrolled in the two groups were assessed at four points: before starting cancer treatment (assessment 1), between 14 and 21 days after commencement of CRT (assessment 2), completion of cancer treatment (assessment 3), and 3 months from completion of treatment (assessment 4). After the final assessment, the patients in the control group were sensitized about the proposed positivity of exercise in reducing CRF and improving functional capacity.

Primary outcome: CRF was assessed using the SAFE,[14] which contains 12 items measuring the extent and impact of CRF.

Secondary outcome: Functional capacity was assessed by the 6-minute walk test (6MWT), Burr's equation was used for maximal oxygen uptake (VO_{2max}), and grip strength was measured by the hand dynamometer. QoL was assessed using European Organization for Research and Treatment for Cancer- Quality of Life (EORTC QLQ-C30) and Head and Neck Cancer module (HN35), while distress was assessed using the NCCN Distress Thermometer.

Data Analysis

The data were analyzed using Statistical Package for the Social Sciences (SPSS) version 22.0. Age, gender, education, occupation, sociodemographic status, marital status, diagnosis, comorbidities, and treatment schedule were summarized using the frequency and proportions. The chi-squared test and independent *t*-test were used to assess the homogeneity of variance between experimental and control groups. Pearson's correlation analysis was used to find the relationship of CRF with distress, functional capacity, and QoL. Two-factor repeated measures analysis of variance was done to understand the interaction between two factors, namely, the assessment points (four points) and the condition, that is, the experimental and control groups, on the dependent variables. Pairwise comparisons were done separately for the experimental and control groups to understand the differences between the assessment points. Bonferroni correction was used to reduce the chances of obtaining false-positive results (type I errors), as multiple pairwise tests were performed on a single dependent variable. Sphericity, the variances of the differences between all combinations of related groups, was tested using Mauchly's test of sphericity. The Greenhouse–Geisser correction was used wherever Mauchly's test of sphericity was violated.

Results

The study participants' CONSORT (Consolidated Standards of Reporting Trials) flowchart is presented in ►**Fig. 1**. Of 223 oral cavity cancer patients screened for CRF, based on the inclusion criteria, 69 patients were included in the study and were randomized into the experimental ($n=35$) and control ($n=34$) groups. Of the 25 patients excluded, 14 were excluded due to severe CRF ($n=1$), comorbidities ($n=10$), physical disabilities ($n=2$), and mortality ($n=1$), while 11 did not consent to participate. Patients with mild and moderate CRF (41.7%; $n=93$) were eligible for study recruitment. Patients reported no CRF (57.8%;n=129) and those with severe CRF(0.5%;n=1) were excluded from the study.

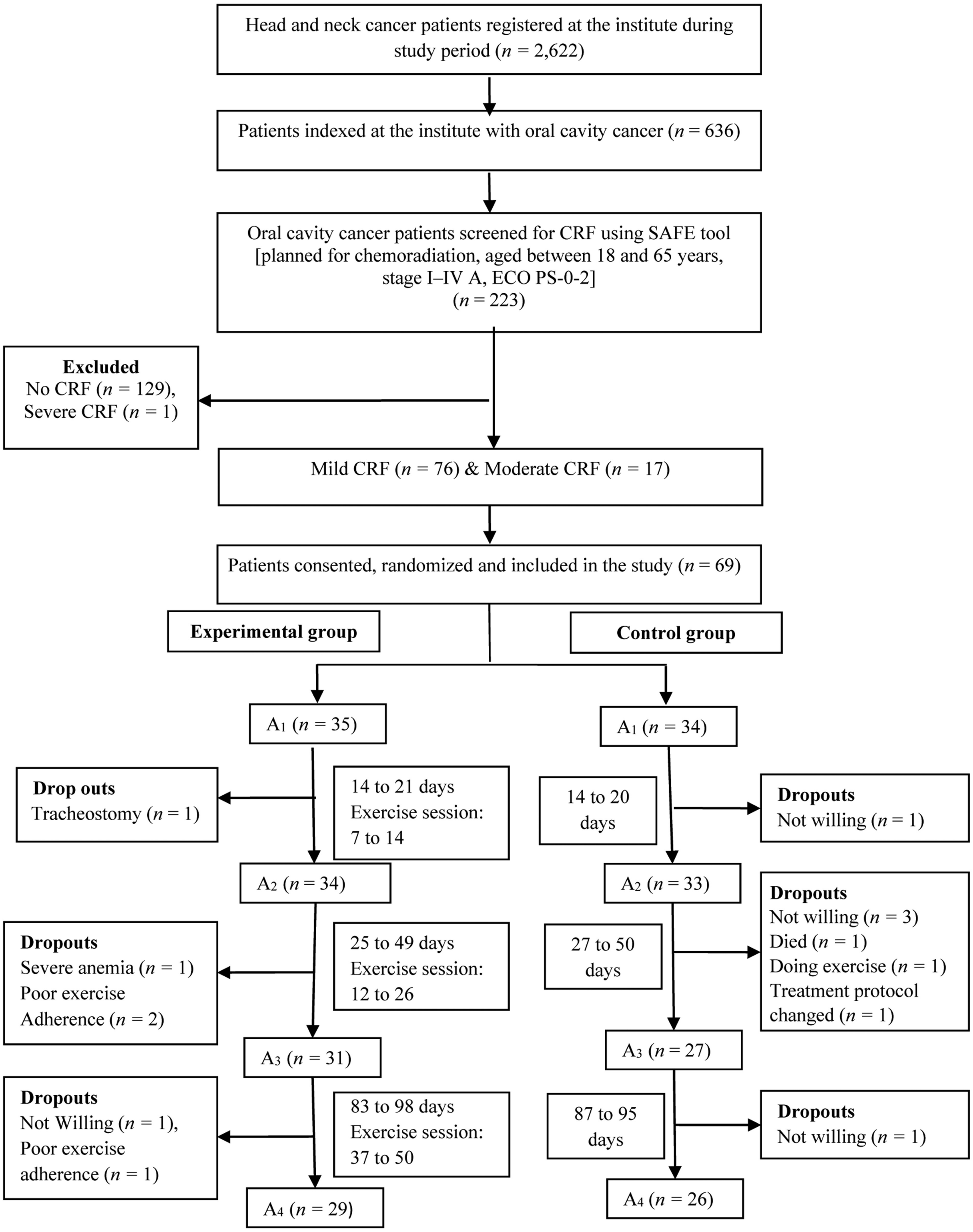

Fig. 1 CONSORT (Consolidated Standards of Reporting Trials) flowchart. A_1, baseline; A_2, between 14 and 21 days of chemoradiotherapy (CRT); A_3, on treatment completion; A_4, follow-up.

It is noted from the ►**Table 1** that the tongue and the cheek are the most commonly affected disease sites among the patients in both groups. With respect to the disease stage, a higher percentage of patients in both groups were in stage IVa. The baseline clinical characteristics and the CRT dose delivered were homogeneous, as noted in ►**Tables 1** and **2**, respectively.

The average duration between A_1 and A_4 was 139.34 days (131–153 days) in the experimental group and 148.04 (134–163 days) in the control group. The patients in the experimental group adhered to their exercise program for 73.48 (SD = 5.12) days. The majority of the patients (93%) adhered to the exercise schedule for 4 days per week. At the

Table 1 Demographic and clinical characteristics of oral cavity cancer patients in the experimental and control group ($N = 69$)

Variable	Categories	Total sample, *n* (%)	Experimental group, *n* (%)	Control group, *n* (%)	*p*-Value
Total		**69 (100)**	**35 (100)**	**34 (100)**	
Age (y)					
Mean (SD)		46.07 (9.23)	45.66 (8.15)	46.5 (10.32)	0.707[a]
Gender					
Male		57 (82.6)	29 (82.9)	28 (82.4)	0.956[b]
Female		12 (17.4)	6 (17.1)	6 (17.6)	
Marital status					
Married		65 (94.2)	34 (97.1)	31 (91.2)	0.520[b]
Single		4 (5.8)	1 (2.9)	3 (8.8)	
Education					
Primary		25 (36.2)	12 (34.3)	13 (38.2)	0.826[b]
Secondary		41 (59.4)	21 (60)	20 (58.8)	
Degree		3 (4.3)	2 (5.7)	1 (2.9)	
Disease site					
Floor of the mouth		3 (4.35)	1 (2.9)	2 (5.9)	0.830[b]
Tongue		36 (52.18)	19 (54.3)	17 (50)	
Cheek		21 (30.43)	12 (34.3)	9 (26.5)	
Retromolar trigone		2 (2.9)	1 (2.9)	1 (2.9)	
Gingiva		7 (10.1)	2 (5.7)	5 (14.7)	
Disease stage					
Stage II		1 (1.4)	–	1 (2.9)	0.262[b]
Stage III		16 (23.2)	6 (17.1)	10 (29.4)	
Stage Iva		52 (75.4)	29 (82.9)	23 (67.6)	
ECOG performance status					
Fully active (0)		55 (79.7)	26 (74.3)	29 (85.3)	0.256[b]
Restricted in physically strenuous activity (1)		14 (20.3)	9 (25.7)	5 (14.7)	

Abbreviations: ECOG, The Eastern Cooperative Oncology Group; *n*, frequency; SD, standard deviation.

[a] *t*-test.

[b] Chi–squared test.

Table 2 Completed treatment regimen of oral cavity cancer patients in experimental and control groups

Treatment regimen	Categories	Total sample, *n* (%)	Experimental group, *n* (%)	Control group, *n* (%)	*p*-Value
Total		**58 (100)**	**31 (100)**	**27 (100)**	
Concurrent CTx/RT					
Once every 3 week CDDP/66 Gy		32 (55.2)	15 (48.4)	17 (63.0)	0.398[a]
Weekly CDDP/66 Gy		21 (36.2)	13 (41.9)	8 (29.6)	
Weekly CDDP/60 Gy +10 Gy neck		2 (3.4)	2 (6.5)	–	
Once every 3 week CDDP/66 Gy		2 (3.4)	–	1 (3.7)	
Weekly carboplatin for 5-week/66 Gy		1 (1.7)	1 (3.2)	1 (3.7)	

Abbreviations: CDDP, cisplatin; CTx, chemotherapy; Gy, gray; RT, radiation therapy.

[a] Chi-squared value.

baseline, there were no significant differences in the fatigue extent and fatigue impact, distress, QoL, and functional capacity between the experimental and control groups.

Cancer-Related Fatigue

Fatigue extent and impact increased during the course of treatment and immediately after the completion of the treatment in both the groups as noted in ►**Table 3**. Statistically significant difference was noted immediately after the completion of treatment and during follow-up, but not during treatment. More than half of the patients in the experimental group had severe CRF during treatment (55.9%) and at completion of treatment (64.5%). A significant effect of exercise intervention on CRF among the patients at completion of treatment ($p < 0.05$) and at follow-up ($p < 0.01$) was reported. The size effect in both fatigue extent ($\eta_p^2 = 0.40$) and impact ($\eta_p^2 = 0.41$) was found to be moderate. Statistically, the interactional effect of four assessments and the two groups was significant in the extent of fatigue ($F = 11.30$; $p < 0.01$) and fatigue impact ($F = 12.14$; $p < 0.01$). The majority of the patients in the two groups experienced moderate level of CRF at baseline. In the experimental group, more than half of the patients had severe CRF during treatment (55.9%) and at completion of treatment (64.5%). But at follow-up, ~69% of the patients experienced moderate CRF and around one-fourth of them had severe CRF. In contrast, the majority of patients in the control group had severe CRF during treatment (90.9%), on completion of treatment (100%), and at follow-up (92.5%). About 69% of patients in the control group had severe impact of CRF during follow-up, whereas only 3.4% of patients in the experimental group had severe impact. ►**Table 4** indicates that experimental group experienced less severity of CRF compared with the control group.

Functional Capacity

A comparison between the two groups showed significant differences at A_2, A_3, andA_4 ($p < 0.01$). The patients in the experimental group covered better 6-minute walk distance (6MWD) than those in the control group after treatment completion and at follow-up. Effect size of intervention on 6MWD is found to be moderate ($\eta_p^2 = 0.22$). There is a significant interaction effect of four assessments and the two groups in the 6MWD ($F = 6.62$). In the experimental group, VO_{2max} decreased during the course of treatment and immediately after the completion of the treatment. It improved during follow-up, but the VO_{2max} of the control group remained the same during A_2, A_3, and A_4. The VO_{2max} of the experimental group was high compared with that of the control group A_2 (2.76**), A_3 (2.50**), and A_4 (2.86**), and the difference was statistically significant. The interactional effect of four assessments and the two groups is significant in the VO_{2max} ($F = 4.36$). The effect size for VO_{2max} ($\eta_p^{\mathbf{2}} = 0.21$) indicated moderate effect size.

The mean value of the left-hand grip strength was 24.86 at A_2, 26.77 at A_3, and 27.1 at A_4 in the experimental group and 22.71 at A_2, 21.76 at A_3, and 23.24 at A_4 in the control group. No significant difference was observed in the values of the right- and left-hand grip strengths at A_4, between the two groups. The effect size of the right- and left-hand grip strengths between the two groups is found to be trivial and moderate, respectively.

Quality of Life

The mean global health status score of the experimental and control groups during the course of treatment was 51.71 and 48.99, respectively. At completion of treatment, it was 51.88 and 45.06, and at follow-up, it was 74.71 and 49.04, respectively, in the experimental and control groups. There was a significant difference between the two groups during treatment, at completion of treatment, and at follow-up in the physical functioning, role functioning, and cognitive functioning ($p < 0.01$). While the functional domains of the experimental group improved at follow-up from that of the baseline, the control group showed a decline compared with the baseline. Moderate effect size was observed in the global health status ($\eta_p^2 = 0.21$), physical functioning ($\eta_p^2 = 0.24$), role functioning ($\eta_p^2 = 0.21$), emotional functioning ($\eta_p^2 = 0.20$), and cognitive functioning ($\eta_p^2 = 0.22$) of the experimental group.

The interactional effect of assessments and the two groups is significant in symptoms of CRF ($F = 4.16$), pain ($F = 6.27$), dyspnoea ($F = 5.55$), insomnia ($F = 4.10$), appetite loss ($F = 6.68$), constipation ($F = 4.90$), and diarrhea ($F = 3.06$). Moderate effect size was observed in nausea ($\eta_p^2 = 0.24$), pain (0.21), constipation (0.21), diarrhea (0.25), and financial difficulties (0.21).

Irrespective of the group, the site-specific issues of HNCs worsened during treatment and at completion, while the same reduced at follow-up in the experimental group. There was a significant difference in the levels of pain, swallowing, speech, and social contact ($p < 0.01$) at baseline and at follow-up in the experimental group.

The two groups differed significantly in the levels of pain, swallowing, and mouth opening during the course of treatment, at completion of treatment, and at follow-up at ($p < 0.01$).

Distress

The mean distress score of the experimental and control groups was found to be 3.34 and 3.02, respectively. Although the mean distress score of the experimental group increased during the course of treatment and immediately after the completion of the treatment, the distress scores decreased during follow-up.

Interrelation of CRF, Distress, Functional Capacity, and QoL

A significant inverse relationship was found between the 6MWD and CRF extent and impact. While the CRF extent and impact were inversely related to the physical, role, and emotional functional domains of QoL, the VO_{2max} was positively related with the global health status ($r = 0.263$). Similarly, the right-hand grip strength was positively correlated to the physical functioning of QoL, as shown in ►**Table 5**.

Table 3 Comparison between four assessments and study groups, means, SDs, *t* values, and effect size for CRF, distress, functional capacity, and QoL of oral cavity cancer patients

Variable	Assessments								ANOVA interaction (*F*-Value)	Partial eta squared
	A_1		A_2		A_3		A_4			
	M (SD)	*t*-Value	M (SD)	*t*-Value	M (SD)	*t*-Value	M (SD)	*t*-Value		
Fatigue extent^{a}										
Experimental	3.77($^{b)(c)(d)}$ (1.21)	0.51^{NS}	5.62 (2.00)	0.71^{NS}	6.52$^{(d)}$ (2.12)	2.11^{b}	4.72 (1.33)	3.10^{c}	11.30^{c,d}	0.40
Control	3.82($^{b)(c)(d)}$ (1.11)		7.70$^{(c)(d)}$ (1.92)		9.30 (1.29)		7.58 (2.02)			
Fatigue impact^{a}										
Experimental	7.77 (4.22)	0.24^{NS}	9.35$^{(c)(d)}$ (3.97)	0.52^{NS}	9.71 (2.75)	2.53^{b}	7.24 (2.81)	3.75^{c}	12.14^{c,d}	0.41
Control	8.35$^{(b)(c)}$ (3.44)		12.70 (3.08)		14.37 (3.39)		13.80 (2.82)			
Distress^{a}										
Experimental	3.34$^{(c)}$ (1.21)	0.16^{NS}	3.76$^{(c)}$ (1.10)	0.29^{NS}	4.09 (1.16)	0.69^{NS}	3.03 (0.73)	0.05^{NS}	0.62^{NS}	0.19
Control	3.02($^{b)(c)(d)}$ (1.05)		3.66 (1.16)		4.81 (1.30)		3.65 (1.26)			
Functional capacity: 6-min walk distance (m)										
Experimental	448.03$^{(c)}$ (74.51)	0.61^{NS}	425.00 (88.40)	2.80^{c}	418.68$^{(d)}$ (71.97)	2.72^{c}	448.72 (59.06)	2.86^{c}	6.62^{b,d}	0.22
Control	444.97($^{b)(c)(d)}$ (94.66)		374.36 (84.24)		351.48 (64.44)		335.00 (60.34)			
VO_2 max										
Experimental	48.94($^{b)(c)(d)}$ (4.10)	0.13^{NS}	40.13 (4.34)	2.76^{c}	39.84 (4.49)	2.50^{b}	41.93 (3.62)	2.86^{c}	4.36^{b,d}	0.21
Control	47.03($^{b)(c)(d)}$ (4.88)		37.09 (4.50)		37.37 (4.79)		37.50 (5.03)			
Hand grip, right										
Experimental	28.29 (12.93)	0.63^{NS}	26.76 (12.01)	2.23^{b}	26.61 (12.50)	2.20^{b}	26.72 (11.49)	1.20^{NS}	1.95^{NS}	0.24
Control	26.28($^{b)(c)(d)}$ (10.81)		23.07 (7.91)		22.92 (8.04)		23.49 (7.90)			
Hand grip, left										
Experimental	27.51 (13.00)	0.33^{NS}	24.86 (12.65)	2.10^{b}	26.77 (11.79)	2.43^{b}	27.18 (11.25)	1.25^{NS}	2.70^{NS}	0.18
Control	25.66$^{(c)}$ (11.24)		22.71 (8.58)		21.76 (9.35)		23.24 (8.57)			
EORTC QoL: global health status										
Experimental	58.81$^{(d)}$ (19.69)	0.37^{NS}	51.71$^{(c)(d)}$ (14.61)	2.16^{b}	51.88 (13.38)	1.99^{b}	74.71 (10.32)	2.63^{c}	6.66^{c,d}	0.21
Control	55.88$^{(c)}$ (17.22)		48.99 (15.55)		45.06 (14.10)		49.04 (22.52)			
Physical functioning										
Experimental	87.81$^{(b)(c)}$ (16.12)	0.13^{NS}	78.63 (20.48)	2.90^{c}	72.90$^{(d)}$ (18.37)	2.14^{b}	83.91 (16.38)	2.01^{b}	3.67^{b,d}	0.24
Control	82.75$^{(c)}$ (19.77)		76.36 (19.44)		66.42 (25.65)		60.26 (27.48)			

(*Continued*)

Table 3 (*Continued*)

Variable	Assessments								ANOVA interaction (*F*-Value)	Partial eta squared
	A$_1$		A$_2$		A$_3$		A$_4$			
	M (SD)	*t*-Value	M (SD)	*t*-Value	M (SD)	*t*-Value	M (SD)	*t*-Value		
Role functioning										
Experimental	86.67$^{(b)(c)(d)}$ (22.43)	0.86^{NS}	81.86 (20.25)	2.37^{b}	64.52 (18.63)	2.02^{b}	86.78 (15.67)	2.86^{c}	4.90^{b,d}	0.21
Control	84.80$^{(c)}$ (21.06)		77.27 (24.58)		70.37 (22.80)		66.03 (21.84)			
Emotional functioning										
Experimental	79.52 (18.56)	0.00^{NS}	78.92 (14.82)	0.50^{NS}	77.42 (13.64)	0.20^{NS}	83.91 (10.89)	0.01^{NS}	2.20^{NS}	0.20
Control	87.25$^{(c)(d)}$ (10.10)		75.25 (20.14)		73.46 (16.99)		66.35 (21.14)			
Cognitive functioning										
Experimental	91.90$^{(c)(d)}$ (14.7)	0.68^{NS}	86.27 (19.45)	2.91^{c}	77.96 (17.94)	2.46^{b}	94.25 (12.81)	2.90^{c}	7.37^{c,d}	0.22
Control	91.18$^{(c)}$ (15.48)		81.31 (21.55)		82.10 (16.61)		73.72 (21.17)			
Social functioning										
Experimental	70.48 (30.27)	0.42^{NS}	71.08 (20.23)	0.19^{NS}	74.73 (19.18)	0.54^{NS}	81.61 (18.00)	0.04^{NS}	2.33^{NS}	0.24
Control	70.10 (34.02)		69.19 (26.06)		77.16$^{(d)}$ (20.22)		63.46 (23.57)			
Fatigue^{a}										
Experimental	29.84 (20.12)	0.51^{NS}	31.37 (18.64)	2.59^{c}	41.22$^{(d)}$ (15.23)	2.00^{b}	27.59 (23.68)	3.10^{c}	4.16^{b,d}	0.17
Control	26.80$^{(d)}$ (17.75)		30.30 (18.48)		41.98 (27.96)		50.43 (24.99)			
Nausea vomiting^{a}										
Experimental	12.38$^{(c)}$ (16.83)	0.55^{NS}	17.16 (13.90)	0.95^{NS}	27.96 (16.32)	0.21^{NS}	18.97 (18.75)	0.11^{NS}	2.44^{NS}	0.24
Control	12.75$^{(c)(d)}$ (19.27)		20.71 (16.68)		29.63 (22.32)		35.26 (25.09)			
Pain^{a}										
Experimental	29.05 (22.63)	0.65^{NS}	28.92 (20.23)	2.19^{b}	32.80$^{(d)}$ (17.99)	2.07^{b}	16.09 (12.18)	2.68 ^{c}	6.27^{c,d}	0.21
Control	22.06$^{(d)}$ (23.10)		31.31 (25.26)		33.33 (26.55)		42.95 (26.32)			
Dyspnoea^{a}										
Experimental	5.71$^{(c)}$ (17.12)	0.97^{NS}	11.76 (10.13)	2.25^{b}	19.35 (12.40)	2.96^{c}	15.75 (12.81)	2.05^{b}	5.55^{c,d}	0.19
Control	5.88$^{(b)(c)}$ (15.28)		17.17 (22.23)		27.16 (24.52)		33.33 (28.28)			
Insomnia^{a}										
Experimental	18.10 (30.6)	0.52^{NS}	26.47 (15.66)	0.96^{NS}	27.96$^{(d)}$ (19.43)	0.62^{NS}	12.64 (8.71)	2.36^{b}	4.10^{b,d}	0.18
Control	22.55$^{(d)}$ (25.58)		28.28 (25.16)		39.51 (20.74)		42.31 (25.91)			

Table 3 (*Continued*)

Variable	Assessments								ANOVA interaction (*F*-Value)	Partial eta squared
	A_1		A_2		A_3		A_4			
	M (SD)	*t*-Value	M (SD)	*t*-Value	M (SD)	*t*-Value	M (SD)	*t*-Value		
Appetite loss^{a}										
Experimental	25.71 (36.23)	0.01^{NS}	28.43 (16.12)	0.76^{NS}	31.18 (19.12)	0.00^{NS}	17.24 (12.12)	2.10^{b}	3.68^{b,d}	0.19
Control	18.63$^{(d)}$ (20.4)		23.23 (14.27)		38.27 (30.24)		50.00 (32.99)			
Constipation^{a}										
Experimental	25.71 (36.23)	0.00^{NS}	20.59 (23.23)	0.54^{NS}	27.96 (19.43)	0.62^{NS}	16.09 (12.95)	2.06^{b}	4.90^{b,d}	0.21
Control	13.73$^{(d)}$ (23.38)		24.24 (20.87)		33.33 (22.64)		29.49 (18.79)			
Diarrhea^{a}										
Experimental	7.62 (19.94)	0.36^{NS}	13.73 (8.56)	0.14^{NS}	12.90 (6.50)	0.01^{NS}	10.34 (5.69)	2.76^{b}	3.06^{b,d}	0.25
Control	10.78$^{(d)}$ (21.2)		22.22 (13.07)		24.69 (15.08)		37.18 (28.79)			
Financial difficulties^{a}										
Experimental	37.41 (39.41)	0.42^{NS}	46.08 (31.79)	0.88^{NS}	44.09 (26.36)	0.25^{NS}	46.67 (40.68)	0.15^{NS}	0.91^{NS}	0.21
Control	42.16 (35.11)		37.37 (33.08)		33.33 (34.59)		39.74 (34.01)			
Pain^{a}										
Experimental	36.67$^{(c)}$ (21.21)	0.10^{NS}	44.12 (19.41)	2.27^{b}	56.99 (19.84)	2.42^{b}	28.16 (18.15)	2.68^{c}	8.50^{c,d}	0.23
Control	27.21(${}^{b)(c)(d)}$ (14.9)		42.17 (22.62)		53.40 (24.70)		55.13 (21.61)			
Swallowing^{a}										
Experimental	26.19$^{(c)(d)}$ (25.73)	0.45^{NS}	37.75 (23.14)	2.54^{b}	50.00 (19.48)	2.32^{b}	18.97 (12.14)	2.18^{b}	6.13^{c,d}	0.20
Control	19.61(${}^{b)(c)(d)}$ (21.08)		45.96 (26.69)		48.46 (23.57)		62.82 (77.50)			
Senses problem^{a}										
Experimental	25.24$^{(c)}$ (26.92)	0.62^{NS}	33.33 (24.95)	0.92^{NS}	41.40 (17.67)	0.28^{NS}	30.46 (24.82)	0.99^{NS}	1.25^{NS}	0.22
Control	21.08$^{(c)}$ (29.95)		37.88 (23.67)		50.00 (25.31)		44.23 (26.22)			
Speech problem^{a}										
Experimental	21.59 (21.03)	0.15^{NS}	28.10$^{(d)}$ (19.95)	0.70^{NS}	29.39 (16.86)	0.67^{NS}	14.18 (11.07)	0.00^{NS}	5.88^{c,d}	0.21
Control	13.07$^{(b)(c)}$ (16.5)		28.62 (22.40)		34.16 (16.85)		32.05 (22.07)			
Trouble with social eating^{a}										
Experimental	23.10 (26.43)	0.21^{NS}	31.62$^{(d)}$ (20.39)	0.75^{NS}	33.87 (17.99)	0.01^{NS}	19.25 (12.22)	0.06^{NS}	5.16^{c,d}	0.18
Control	14.71$^{(b)(c)}$ (14.8)		31.82 (21.19)		37.35 (24.28)		37.50 (23.12)			

(*Continued*)

Table 3 (*Continued*)

Variable	Assessments								ANOVA interaction (*F*-Value)	Partial eta squared
	A_1		A_2		A_3		A_4			
	M (SD)	*t*-Value	M (SD)	*t*-Value	M (SD)	*t*-Value	M (SD)	*t*-Value		
Trouble with social contact[a]										
Experimental	$19.05^{(c)}$ (22.76)	0.10^{NS}	24.31 (19.75)	0.42^{NS}	31.18 (18.65)	0.28^{NS}	14.25 (10.03)	0.00^{NS}	$6.9^{c,d}$	0.21
Control	$10.78^{(b)(c)}$ (15.13)		28.89 (21.58)		32.35 (20.14)		38.97 (23.14)			
Teeth[a]										
Experimental	$14.29^{(c)}$ (23.27)	0.19^{NS}	31.37 (29.52)	0.53^{NS}	47.31 (33.08)	0.22^{NS}	24.14 (30.72)	0.40^{NS}	1.52^{NS}	0.22
Control	$23.53^{(b)}$ (29.0)		35.35 (27.56)		46.91 (28.13)		44.87 (32.58)			
Opening mouth[a]										
Experimental	$49.52^{(c)}$ (31.6)	0.38^{NS}	50.00 (28.72)	2.13^{b}	69.89 (21.69)	2.43^{b}	55.17 (28.55)	2.72^{c}	$5.10^{c,d}$	0.18
Control	$36.27^{(d)}$ (30.0)		52.53 (35.38)		56.79 (30.40)		75.64 (24.14)			
Dry mouth[a]										
Experimental	$25.71^{(c)}$ (33.41)	0.01^{NS}	44.12 (26.86)	0.09^{NS}	48.39 (20.79)	0.49^{NS}	37.93 (21.31)	0.00^{NS}	$4.91^{c,d}$	0.18
Control	$13.73(^{b)(c)(d)}$ (21.89)		47.47 (33.36)		58.02 (25.47)		57.69 (30.63)			
Sticky saliva[a]										
Experimental	$28.57^{(c)}$ (35.37)	0.27^{NS}	39.22 (23.88)	0.74^{NS}	50.54 (24.14)	0.45^{NS}	32.18 (24.36)	0.01^{NS}	1.56^{NS}	0.22
Control	$22.55^{(b)(d)}$(28.09)		45.45 (28.64)		53.09 (21.20)		47.44 (31.51)			
Coughing[a]										
Experimental	22.86 (25.27)	0.59^{NS}	27.45 (25.25)	0.50^{NS}	25.81 (26.81)	0.69^{NS}	13.79 (24.42)	0.04^{NS}	2.50^{NS}	0.24
Control	$18.63^{(b)}$ (23.48)		37.37 (29.76)		33.33 (29.23)		33.33 (33.99)			
Felt ill[a]										
Experimental	$20.95^{(c)}$ (24.3)	0.17^{NS}	33.33 (27.21)	2.55^{b}	47.31 (28.25)	2.71^{c}	32.18 (10.84)	0.00^{NS}	1.20^{NS}	0.23
Control	$11.76^{(c)(d)}$ (18.13)		30.30 (26.82)		45.68 (30.86)		44.87 (26.57)			

Note: Superscripts with the mean values indicate multiple comparisons between the assessment using Bonferroni corrections.

Abbreviations: A_1(a), baseline; A_2(b), between 14 and 21 days of chemoradiotherapy (CRT); A_3(c), on completion of treatment; A_4(d), 3 months of follow-up. M, Mean. NS, Not significant. SD, Standard deviation.

[a] Lower scores are beneficial.

[b] $p < 0.05$.

[c] $p < 0.01$.

[d] Statistically significant after Bonferroni correction.

Table 4 Percentage distribution of severity of cancer-related fatigue (CRF) among oral cavity cancer patients of experimental and control group during the four assessments

CRF	Experimental, *n* (%)				Control, *n* (%)			
	A_1 ($n = 35$)	A_2 ($n = 34$)	A_3 ($n = 31$)	A_4 ($n = 29$)	A_1 ($n = 34$)	A_2 ($n = 33$)	A_3 ($n = 27$)	A_4 ($n = 26$)
Fatigue extent								
Mild	7 (20.0)	1 (2.9)	–	1 (3.4)	6 (17.6)	1 (3.0)	–	–
Moderate	28 (80.0)	14 (41.2)	11 (35.5)	20 (69.0)	28 (82.4)	2 (6.1)	–	2 (7.7)
Severe		19 (55.9)	20 (64.5)	8 (27.6)		30 (90.9)	27 (100)	24 (92.3)
Fatigue impact								
Mild	11 (31.4)	6 (17.6)	2 (6.5)	7 (21.4)	8 (23.5)	–	1 (3.7)	–
Moderate	16 (45.7)	24 (70.6)	24 (77.4)	21 (72.4)	20 (58.8)	15 (45.5)	5 (18.5)	8 (30.8)
Severe	8 (22.9)	4 (11.8)	5 (16.1)	1 (3.4)	6 (17.6)	18 (54.5)	21 (77.8)	18 (69.2)

Abbreviations: A_1, baseline before starting cancer treatment; A_2, assessments between 14 and 21days; A_3, on completion of cancer treatment; A_4, 3 months of follow-up.

Discussion

The findings of the present study show that a structured exercise intervention was effective in mitigating CRF in its extent and impact, while also improving the QoL and functional capacity of oral cavity cancer patients. The experimental group in the present study recorded a decrease in the extent of CRF and its impact experienced during and at follow-up treatment. These findings are in line with the existing global literature emphasizing the constructive effect of long-term exercise intervention on CRF.[15–19] Similar findings have been reported in studies from an Indian context, stating significant reduction in CRF post 6 weeks of aerobic exercise intervention[20] and that patients with no exercise report intensification of CRF symptoms as compared with the experimental group.[19,21–23] These findings could be attributed to the fact that exercise mitigates CRF and may alleviate the combined effects of toxic treatment and decreased levels of activity during treatment that reduce the capacity for physical performance. The literature emphasizes improved QoL, optimistic feelings, and reduced CRF in exercise intervention.[19,20,23,24]

The duration and frequency of exercises reported in the present study to understand the long-term effects of exercise therapy were analogous to the exercise schedules described in the studies included in a meta-analysis.[3] The effect size for extent of fatigue ($\eta_p{}^2 = 0.40$) and its impact ($\eta_p{}^2 = 0.41$) was found to be moderate in this study. This is in line with the findings of the earlier studies which indicated that a clinically pertinent impact on alleviation of CRF symptoms after exercise intervention with the effect size of ($\eta_p{}^2 = 0.44$) and effect size being ($\eta_p{}^2 = 0.33$), respectively.[17,25]

The present study reported no significant difference in the right- and left-hand grips, despite the higher mean values in the experimental group. This finding is in contrast with the study reporting a significant increase in the handgrip within and between two groups of breast cancer survivors, with one group receiving yoga with aerobic exercise and the other receiving aerobic exercise alone.[26]

The results of this study indicate an increase in the mean values of the VO_{2max} between the experimental and control groups at the end of the study. Many studies have demonstrated that structured exercise intervention during therapy, on completion of treatment, and in the follow-up period significantly increased the VO_{2max} in oral cavity cancer patients.[16,27,28] The results of earlier research helped infer that the VO_{2max} of cancer patients improved as a result of any type of exercise training regardless of the nature of treatment, although the effect size may vary with different forms of exercise.[29–31]

The present study shows that patients in the experimental group covered significantly greater 6MWD during treatment. This is in line with the 8-minute single-stage walking test conducted among women treated for breast cancer stating a significantly increased aerobic fitness in the intervention group including both exercise and exercise-placebo groups than in the control group after 8 weeks.[32] 6MWT is a reliable tool and is significantly related to VO_{2max}, which is appropriate to be used among cancer patients.[33] The results of our study are in line with the studies done with a similar 5-week exercise program in myeloma patients during chemotherapy[34] and an Indian study done among HNC patients who underwent a 6-week exercise program.[35] Both studies found a significant decrease in the 6MWD in the control group. Researches on 6MWT, similar to our study, have reported globally that consistent exercise enhances the functional status in cancer patients.[20,23,35,36]

The results of the present study establishes a high functional status among patients and this is promising as the literature suggests functional status as a significant predictor of survival.[37] Previous studies have emphasized that exercise has a positive outcome on endurance and stamina by achieving better functional capacity and can thus bring in favorable changes in the health status of cancer patients.[22,32,38–41] Sprod et al also reported improved functional capacity with enhanced cardiovascular endurance and diminished fatigue and depression in breast cancer patients irrespective of the duration of training given.[42]

Table 5 Interrelation of cancer-related fatigue (CRF), distress, functional capacity, and QoL of oral cavity cancer patients at baseline ($N = 69$)

CRF		Distress	Functional capacity				EORTC quality of life					
CRF extent	CRF impact		Hand grip strength, right	Hand grip strength, left	6-min walk distance	VO_{2max}	Global health status	Physical function	Role function.	Emotional function	Cognitive function	Social functioning
1												
0.578^{a}	1											
–0.093	0.008	1										
–0.229	–0.097	0.064	1									
–0.165	–0.024	0.090	0.962^{a}	1								
–0.270^{b}	–0.298^{b}	–0.154	–0.156	–0.157	1							
0.191	0.136	–0.101	0.074	0.025	0.414^{a}	1						
–0.164	–0.188	–0.370^{a}	0.127	0.027	0.067	0.263^{b}	1					
–0.346^{a}	–0.345^{a}	–0.130	0.293^{b}	0.267^{b}	0.169	0.171	0.369^{a}	1				
–0.284^{b}	–0.338^{a}	0.091	0.164	0.125	–0.035	–0.018	0.149	0.347^{a}	1			
–0.296^{b}	–0.276^{b}	0.063	–0.040	–0.017	–0.009	–0.165	0.104	0.262^{b}	0.337^{a}	1		
–0.213	–0.238^{b}	0.023	0.190	0.207	–0.088	0.127	0.235	0.313^{a}	0.039	0.309^{a}	1	
–0.086	–0.223	0.207	0.067	0.037	0.118	0.124	0.134	0.264^{b}	0.230	0.212	0.099	1

Abbreviation: EORTC, European Organization for Research and Treatment for Cancer.
Note: The values represent correlation coefficient "*r*."
$^{a}p < 0.01$.
$^{b}p < 0.05$.

Further, this study showed a significant decrease in the mean values of distress score in the experimental group, which is consistent with the results of other studies.[22,23] Comparable results of the association between designed exercise programs and improvement of QoL were found in this study and is supported by the literature.[30,32,35,43–45]

The strength of this study is that the patients who experienced CRF before their cancer treatment were chosen and examined the effect of structured exercise intervention during the course of treatment and at follow-up. This study is also unique in that it performed an extensive analysis on the correlation between CRF, distress, QoL, and functional capacity among oral cavity cancer patients. Results indicate a positive correlation between 6MWD, fatigue extent, and fatigue impact.

The present study suggests that structured exercise intervention has a significant positive influence on the impact and extent of CRF, most aspects of QoL, and on the functional capacity of the patients. This may be attributed to the fact that swallowing pathway and respiratory functions are usually affected in oral cavity cancer patients undergoing CRT. During the course of the treatment, this group of patients often depend on liquid diet or might even require nasogastric tube feeding as they develop oral mucositis. Oral mucositis is a major cause of pain and undernutrition in patients with oral cavity cancer. The exercise schedules add advantage by enhancing the functional status. The study also suggests that exercise is an efficient strategy in the management of CRF regardless of the type of treatment and in maintaining the status of physical activity.

Limitations and Implications of the Study

The small sample size limits the generalization of the study findings. Oral mucositis as a major cause of pain and undernutrition during CRT in patients with oral cavity cancer is not deeply explored.

The study found that a moderate-intensity structured exercise improves the functional capacity with concomitant reduction in CRF regardless of the time of treatment. Therefore, it can be made the standard of care in cancer rehabilitation. Although oral mucositis can cause significant pain and undernutrition during CRT in patients with oral cavity cancer, exercise sessions are feasible and improve the functional capacity and treatment completion.

Future research can focus on multicentric RCTs with long-term follow-ups, after home-based exercise intervention to mitigate CRF.

Conclusion

The present study observed a decrease in CRF with exercise in oral cavity cancer patients during and after concurrent CRT. Exercise also led to significant reduction in distress and significant improvement in health-related QoL and functional capacity in oral cavity cancer patients, as indicated by improved 6MWD, VO_{2max}, and hand grip.

Ethical Approval

The approval for the project was submitted to the Cancer Institute Ethical Committee. This study followed the principles of the Declaration of Helsinki and was approved by the ethical committee meeting dated February 13, 2013. The study was conducted at the Regional Cancer Centre, Chennai.

Conflict of Interest

None declared.

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Relationship between Psychological States and Coping in Reproductive Cancer Patients in the Context of the Pandemic

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Abstract

Introduction Cancer is known as a disease caused by an uncontrolled division of abnormal cells with the potential to proliferate and destroy body tissues. While it is not uncommon to observe changes in psychological states among patients with cancer, the pandemic situation has been reported to have an impact more severely.

Objective This study attempts to understand the psychological problems of cancer patients, and the process of coping adopted by reproductive cancer patients during the period of the pandemic.

Materials and Methods This study uses a correlation research design and the tools used for assessment were the four-dimensional symptom questionnaire and Brief COPE inventory. Through nonrandom sampling, a sample of 120 cancer patients diagnosed with reproductive cancer, both male and female from the regional cancer center and private cancer hospitals in Hyderabad, was recruited for the pandemic period from May 2020 to September 2021. Descriptive statistics, correlation, and regression statistical analysis methods were implemented.

Results Significant negative correlation was observed between psychological states and coping. Using multiple linear regression analysis, it was found that distress and depression predict problem-solving coping, distress and anxiety predict emotion-solving coping, and distress predicts adaptive coping.

Conclusion This study examines the psychological factors and coping methods in adapting to the dual challenges of illness and potential risk of infection transmission, and emphasizes designing an effective intervention. During the coronavirus disease 2019 crisis, the lack of support through psychological counseling to address their coping mechanisms to face the challenges is also glaring.

Keywords

- COVID-19
- psychological states
- coping
- psychological distress
- depression
- anxiety

Introduction

A chronic illness like cancer has multiple effects that cross the physiological framework and manifest themselves in psychosocial aspects.[1,2] Many cancer patients suffer from psychological distress, psychosomatic disorders, and psychological crisis during the stages of cancer diagnosis and different phases of treatment.[3,4] Adding to this, the outbreak of coronavirus disease 2019 (COVID-19) has disrupted health services,[5] caused a delay in medical procedures,[6,7] and led to medical complications[8] and cumulative disease burden.[9] As known when compared with the general

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population, the immune-suppressed status of cancer patients due to advanced stage of malignancy or cancer treatments increases the risk of COVID-19 infection transmission.[10] Thus, COVID-19 is experienced as a "syndemic"—a co-occurring, synergistic pandemic that interacts with and exacerbates their existing noncommunicable disease and social conditions.[11] A syndemic exists when risk factors or comorbidities are interwined, interactive, and cumulative-aggravating the disease burden and additively increasing the adverse effects.

This study observes psychological states and different coping strategies in patients diagnosed with cancer during the period of a pandemic. A psychological state is a mental condition in which the quality of the state is relatively constant, even though the state itself may be dynamic. Terluin et al identified four dimensions that describe psychological states: distress, depression, anxiety, and somatization.[12] In simple terms, psychological distress is described as a state of emotional suffering associated with stressors and demands that are difficult to cope with, which is indicative of physical, mental, or emotional exhaustion. Depression causes feelings of sadness, and or loss of interest in activities that one enjoyed before. Anxiety is the body's natural response to stress such as feelings of fear or apprehension about what's to happen; somatization is the expression of psychological or emotional factors as physical (somatic) symptoms. A coping strategy is defined as "a response aimed at diminishing the physical, emotional, and psychological burden linked to stressful life events and daily hassles."[13]

A detailed literature review has been conducted for the study. Cancer is one of the most widely studied diseases that cause significant psychological distress.[14–17] According to Oncology care, NCCN Guidelines (2019), "Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disability such as depression, anxiety, panic attacks, social isolation, and existential and spiritual crisis."[18] This is seen in greater magnitude in the current syndemic situation. Different studies emphasize the role of factors such as a change in lifestyle,[19,20] lack of social support or social interaction,[21] employment issues,[22] and others in the manifestation of certain mental health issues.[23,24]

A systematic review revealed that COVID-19 adversely affected the psychological health of cancer patients. Fear of COVID-19, fear of disease progression, disruption of oncology services, cancer stage, and immune-compromised status were the most common causes of psychological distress in cancer patients, which can influence patients' decisions about treatment as reported in the study.[25] A systematically reviewed community-based studies estimate the prevalence of depression during COVID-19 from 7.45 to 48.30%.[26] Another cross-sectional study observed anxiety and depression are very common and employment loss during a pandemic is positively associated with greater depressive symptoms.[27] An Indian study analyzed COVID-19 induced work stress and found that role overload, family distraction, changes in lifestyle choices, and occupational discomfort were significant predictors of distress during a lockdown.[28]

Research indicates that the potential mental health effects of COVID-19 might be associated with the primary effects of epidemic disease outbreaks and secondary effects of economic recessions/depression, loneliness, quarantine, and social isolation.[29] Important to mention here is the "process of stress amplification," which explains the cumulative burden when two stressors combine and cause multiplicative effects on mental health.[30] Research studies have attempted to explore coping in cancer patients.[31,32] Psychological and coping responses were analyzed in a review-research in the context of the COVID-19 situation, comprising a narrative synthesis of 24 papers and the common themes that emerged in psychological responses are not only anxiety, fear, depression, anger, guilt, grief, loss, post-traumatic stress, and stigmatization, but also a greater sense of empowerment and compassion toward others. A comprehensive systematic review strengthened the evidence for an association between psychological coping and cancer outcome.[33] Research throws light on an individual's coping style and explains that fighting spirit has improved survival rates even in the advanced stage of leukemia.[34] Another study observed that individual coping style determines the intensity of trauma-related symptoms in cancer, where destructive coping style and emotional reactivity account for 55% of the variance of general post-traumatic stress symptoms.[35] Similarly, Laskowska reported with the study findings that a destructive style of coping with stress is less beneficial for the adaptation to cancerous disease and may influence the development of post-traumatic symptoms in persons diagnosed with cancer.[36,37] As mentioned above, research studies related to stress and coping in cancer patients are widely reported across the countries. However, there seems to be a need to explore the psychological states of patients with cancer and their coping mechanism during the challenging phases of the pandemic, especially in the Indian scenario.

Research Objective

Based on the above review findings, the following objectives have been formed concerning the person diagnosed with reproductive cancer with special reference to the pandemic situation.

1. To examine the psychological states of patients diagnosed with reproductive cancer.
2. To examine coping adopted by patients diagnosed with reproductive cancer.
3. To know the relationship between psychological states and coping in patients diagnosed with reproductive cancer.
4. To find out predictors of coping among patients diagnosed with reproductive cancer

Materials and Methods

Research Design—This study is retrospective, and uses a corelational design to understand the relationship between psychological states and coping among reproductive cancer patients. The data was collected from regional cancer hospitals and private cancer hospitals in the twin cities of Hyderabad in Telangana state, from May 2020 to September 2021.

Participants: Nonrandom sampling, more specifically convenient sampling, was done; 120 patients diagnosed with reproductive cancer were recruited from hospitals in Hyderabad for the study. Both males and females were diagnosed with reproductive cancer (cancer in the testes, prostate, and penis in males; cancer of the uterus, cervix, ovary, vagina, and fallopian tube in females) of stages 1, 2, and 3, and aged between 18 and 65 years were included in the study.

However, patients with uncontrolled or recurrence of cancer, patients with advanced stages of cancer (stage 4), and patients with a history of other types of malignancies, or known with psychological morbidity (schizophrenia, paranoid disorder, bipolar mood disorder) were excluded from the study. It was ensured by the patients and caregivers that they have not been diagnosed with any psychiatric illness.

Instruments: The psychological instruments used for the study were well-researched tools. The description of tools is as follows.

1. Four-dimensional symptom questionnaire (4DSQ) makes an assessment of distress, anxiety, depression, and somatization in cancer patients. 4DSQ subscales show excellent reliability and validity and Cronbach's α for the four subscales ranged from 0.79 to 0.90.
2. Brief COPE was developed by Carver, a four-point Likert scale consisting of 28 items. It assesses 14 subscales, two items each, which deal with ways a person is coping with stress in his/her life. It shows good reliability and validity. Carver reported and established the reliability and validity of the Brief COPE scale in the original scale (Cronbach's α: 0.570.90).[38]

The psychometric properties of the Brief COPE scale are studied in different contexts.[39,40] A study has categorized these into four-domain problem: focused coping (active coping, planning, and seeking instrumental support), emotion-focused coping (seeking emotional support, positive reframing, and religion), adaptive coping (acceptance and humor), and maladaptive coping (venting, behavioral disengagement, self-distraction, substance use, self-blame, and denial).

Procedure: Data collection has been done after obtaining ethics approval from the parent university and necessary permission from hospital authorities. After obtaining consent from each patient, the measure was administered individually by the researcher. Any doubts or queries from patients were clarified. For the benefit of those who are not comfortable with English, the measures were translated into the vernacular languages (Telugu and Hindi).

Ethical guidelines have been followed for the study. The participants were primarily approached and rapport was generated when the researchers introduced themselves and, the research work's purpose, and other necessary details were told to them. With their consent, psychological instruments were provided and their responses were recorded and complete confidentiality was ensured. Debriefing was done after the procedure.

Statistical Analysis

Descriptive statistics, correlation, and regression statistical analysis methods were implemented. This study used a correlational design to find associations and predictions between psychological states and coping among reproductive cancer patients.

Ethics

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. An approval was taken by Institutional Ethics committee board, School of Medical Sciences, University of Hyderabad, bearing No- UH/IEC/2020/257 for the study.

Results

The following figures portray the analysis of the results starting with descriptive statistics.

►**Fig. 1** displays the diagrammatic representation of the study's distribution of types of reproductive cancer patients. The percentage distribution of types of reproductive cancer patients in this study is as follows. The distribution (n = 120) is as follows: Cervix cancer 60 (50%), Breast cancer 27 (22.5%), Ovarian cancer16 (13.33%), Prostate cancer 5 (4.16%), Endometrial cancer 5 (4.16%), Penis cancer 3 (2.5%), Cancer in vulva 2 (1.6%), Cancer in scrotum 2 (1,6%).

Fig. 1 Pie chart showing distribution of reproductive cancer patients in the sample ($n = 120$). Ca Breast, breast cancer; Ca Cervix, cervical cancer; Ca Endometrium, endometrial cancer; Ca Ovary, ovarian cancer; Ca Penis, cancer in penis; Ca Prost, prostrate cancer; Ca Scrotum, scrotal cancer; Ca Vulva, cancer in vulva.

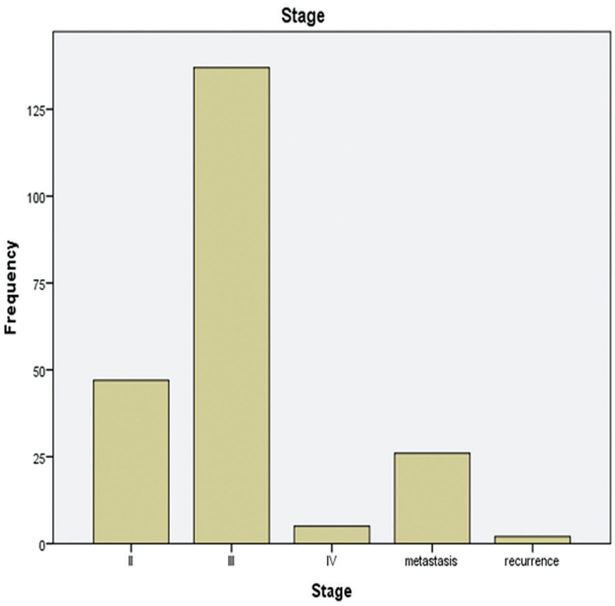

Fig. 2 Bar graph showing the distribution of stages of different types of reproductive cancer in the study. Participants in the study are majorly of reproductive cancer stages 3 and 2.

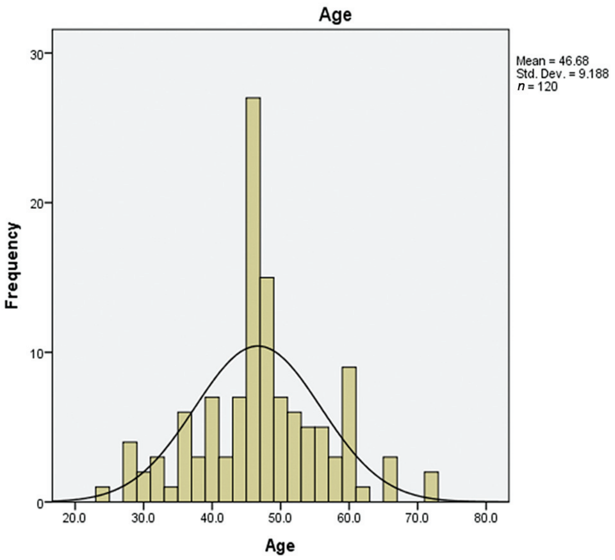

Fig. 3 Bar graph showing age of reproductive cancer patients. Mean age of reproductive cancer patients in the study (*n* = 120).

►**Fig. 2** describes that majority of participants in the study are diagnosed with reproductive cancer stages 3 and 2. Very few cases diagnosed with stage 4, recurrence, and metastasis are included.

►**Fig. 3** displays the normal distribution curve and shows the mean age of reproductive cancer patients is 46.67 years with a standard deviation of 9.33 in the sample ($n = 120$) taken for the study.

The following paragraphs explain the results using statistical analysis.

Objective 1 examined the psychological states of patients diagnosed with reproductive cancer. Accordingly, the psychological states measured using a 4DSQ are distress, depression, anxiety, and somatization.

►**Table 1** demonstrates the mean score of psychological states of patients diagnosed with reproductive cancer. The mean score of distress is 22, somatization is 14, followed by an anxiety score of 9 and the mean depression score of 6. An interpretation of scores is done based on the following description as per the manual. Distress score more than 20 indicates strong elevation; depression score more than 5 indicates strong elevation; anxiety more than 8 indicates moderate elevation; and somatization score more than 10 indicates moderate elevation in psychological states, respectively.

Table1 Mean value of psychological states of patients diagnosed with reproductive cancer

	Mean	SD
DSQ distress	21.79	5.60
DSQ depression	6.33	3.46
DSQ anxiety	8.82	4.62
DSQ somatization	14.43	6.45

Abbreviations: DSQ, dimensional symptom questionnaire; SD, standard deviation.

Objective 2 measured the coping strategies adopted by patients diagnosed with reproductive cancer. In this study, 14 different types of coping are measured using a Brief COPE inventory.

►**Table 2** demonstrates the mean and standard deviation values for the 14 types of coping.

According to the Brief COPE scale, the dimensions are active coping (M = 3.86), planning (M = 3.30), instrumental

Table 2 Types of coping measured using Brief COPE inventory (BCI)

Coping types	Mean	Standard deviation
BCI-active coping	3.86	2.02
BCI-planning	3.30	1.73
BCI-instrumental support	4.73	1.79
BCI-emotional support	6.05	2.31
BCI-positive reframing	2.53	1.60
BCI-religion	4.10	1.81
BCI-acceptance	3.78	1.59
BCI-humor	1.89	0.84
BCI-venting	5.06	1.59
BCI-behavioral disengagement	4.06	1.86
BCI-self-distraction	4.99	1.82
BCI-substance use	1.98	0.80
BCI-self-blame	3.19	1.77
BCI-denial	3.49	1.46

Table 3 Mean values of four types of coping

Types of coping	Mean (M)	Standard deviation (SD)
Problem focused coping	11.88	4.77
Emotion focused coping	12.69	4.46
Adaptive coping	5.70	1.95
Maladaptive coping	22.98	6.04

►**Table 3** shows the Mean values of four broad categories of coping styles.

support (M = 4.73), emotional support (M = 6.05), and positive reframing (M = 2.53), religion (M = 4.10), acceptance (M = 3.78), humor (M = 1.89), venting (M = 5.06), behavioral disengagement (M = 4.06), self-distraction (M = 4.99), substance use (M = 1.98), self-blame (M = 3.19), and denial (M = 3.49).

The Brief COPE measures fourteen different coping strategies that are broadly grouped into four coping types: problem-focused, emotion-focused, adaptive and maladaptive coping. In this study, the maladaptive coping measure is the most common, and adaptive coping is very less seen among reproductive cancer patients (►**Table 3**).

Objective 3 explored the relationship between psychological states and coping in patients diagnosed with reproductive cancer.

The correlation matrix (►**Table 4**) indicates a significant negative correlation between distress and problem-focused coping (−0.52**), emotion-focused coping (−0.34**), and adaptive coping (0.31) in the given sample ($n = 120$) for the study. The results indicate that when distress is high in the sample, the coping types such as problem-focused, emotion-focused coping, and adaptive coping values are low and vice versa. Thus, all values of association between distress and coping indicate a negative relationship at a significant level.

There is a negative correlation established between depression and problem-focused (0.53**), emotion-focused (−0.27**), and adaptive coping (−0.34**) in the study. This signifies that when depression is high, problem-focused, emotion-focused, and adaptive coping measures are low, and vice versa. Thus, all values of association between depression and coping indicate a negative relationship at a significant level.

There is a negative association seen between anxiety and problem-focused (−0.36**), emotion-focused (−0.09), adaptive coping (−0.33**), and maladaptive coping (−0.07), which signify that when anxiety is high, all the above four types of coping measures are low and vice versa. Thus, values of association between anxiety and problem-focused and adaptive coping indicate a significant negative relationship.

There is a negative association seen between somatization and problem-focused (−0.33**) coping and adaptive coping (−0.22**), whereas, there is no association between somatization and two other types of coping such as emotion-focused coping and maladaptive coping Thus, values of association between somatization and problem-focused coping as well as adaptive coping indicate a negative significant relationship.

Objective 4 found predictors of coping strategies in patients diagnosed with reproductive cancer.

Multiple regression analysis was done with problem-focused coping as the criterion, and distress, depression, and anxiety as predictors. The analysis gave rise to three models (►**Table 5**).

In the first model, distress is taken as a predictor and the model significantly explains 27% of the variance in problem-focused coping strategy F (1, 118) = 43.21, $p < 0.001$. In the second model, depression is added as a predictor and the model predicts 31% of the variance F (1, 117) = 26.74, $p < 0.01$, the R square change is 0.05, and the p-value is significant at 0.01 level. In the third model, when anxiety is added as a predictor, the results show that the R square change is not significant. Thus, ►**Table 6** indicates that distress and depression are significant predictors of problem-focused coping.

Table 4 Correlation matrix between psychological states and coping

	4DSQ Ds	4DSQDp	4DSQAx	4DSQSo	BCIPF	BCIEF	BCIA	BCIMA
4DSQDs	1							
4DSQDp	0.736**	1						
4DSQAx	0.632**	0.646**	1					
4DSQSo	0.466**	0.529**	0.634**	1				
BCIPS	−0.518**	−0.526**	−0.359**	−0.330**	1			
BCIES	−0.339**	−0.268**	−0.088	−0.069	0.785**	1		
BCIA	−0.314**	−0.341**	−0.333**	−0.223*	0.700**	0.609**	1	
BCIMA	−0.043	0.079	0.068	0.086	0.568**	0.746**	0.446**	1

Abbreviations: BCIA Brief COPE inventory adaptive; BCIEF, Brief COPE inventory emotion-focused; BCIMA BCI maladaptive; BCIPF, Brief COPE inventory problem-focused; 4DSQ Ds, four-dimensional symptom questionnaire distress; 4DSQ Dp, 4DSQ depression; 4DSQ Ax 4DSQ anxiety; 4DSQ So 4DSQ somatization.

**Significant at 0.01 level.

*Significant at 0.05 level.

Table 5 Summary of multiple linear regression analysis for variables predicting problem focused coping

Model and predictor variables	B	SE B	B	*t*	R^2	ΔR^2
Model 1						
DSQ Ds	−0.44	.07	−0.52	−6.57	0.27	0.27
Model 2						
DSQ Ds	−0.24	0.10	−0.28	−2.52		
DSQ Dp	−0.43	0.16	−0.32	−2.80	0.31	0.05
Model 3						
DSQ Ds	−0.25	0.10	−0.30	−2.52		
DSQ Dp	−0.46	0.17	−0.33	−2.77		
DSQ Ax	−0.05	0.11	0.05	0.45	0.31	0.00

Abbreviations: DSQ Ax dimensional symptom questionnaire anxiety DSQ Ds, DSQ distress; DSQ Dp, DSQ depression; ΔR^2, R^2change; B, unstandardized coefficient; SEB, standardized error of beta; β, standardized coefficient.

* $p < 0.05$.

** $p < 0.01$.

*** $p < 0.001$.

Table 6 Summary of multiple linear regression analysis for variables predicting emotion focused coping

Model and predictor variables	B	SE B	β	*t*	R^2	ΔR^2
Model 1						
DSQ Ds	−0.27	0.07	−0.34	−3.92	0.115	0.115
Model 2						
DSQ Ds	−0.25	0.10	−0.31	−0.24	0.116	0.00
DSQ Dp	−0.05	0.16	−0.04	−0.31		
Model 3						
DSQ Ds	−0.31	0.11	−0.40	−2.98	0.150	0.034
DSQ Dp	−0.18	0.17	−0.14	−1.04		
DSQ Ax	−0.24	0.11	0.25	2.15		

Abbreviations: DSQ Ax dimensional symptom questionnaire anxiety DSQ Ds, DSQ distress; DSQ Dp, DSQ depression; ΔR^2, R^2change; *B*, unstandardized coefficient; SEB, standardized error of beta; β, standardized coefficient.

* $p < 0.05$.

** $p < 0.01$.

*** $p < 0.001$.

Likewise, multiple regression analysis is done where distress, depression, and anxiety are taken as predictors for emotion-focused coping. The analysis gives rise to three models (►**Table 6**). In the first model, distress is taken as a predictor and the model significantly explained 11.5% of the variance in emotion-focused coping, F (1, 118) = 15.35, $p < 0.001$. In the second model, depression is added as a predictor and the model shows 11.6% of the variance emotion-solving coping, F (1, 117) =7.67, and the R square change is zero and hence not significant. In the third model, when anxiety is added as a predictor, the model shows a 15% variance in emotion-solving coping, F (1, 116) =6.80, $p < .05$, and the R square change is found 0.03, and the *p*-value is significant at 0.05 level. Thus, ►**Table 6** shows that distress and anxiety are significant predictors of emotion-focused coping among patients diagnosed with reproductive cancer.

Subsequently, multiple regression analysis is done with adaptive coping as a criterion, and distress, depression, and anxiety as predictors. The analysis gives rise to three models (►**Table 7**). In the first model, distress is taken as a predictor and the model significantly explained 9% of the variance in adaptive coping, F (1, 118) = 12.95, $p < 0.001$. In the second model, depression is added as a predictor and the model shows 11% of the variance in adaptive coping, F (1, 117) =8.36, and the R square change is 0.03 and the *p*-value is not significant. In the third model, when anxiety is added as a predictor, the model shows a 12% of variance in emotion-solving coping, F (1, 116) =6.34, and the R square change is found 0.02, and the *p*-value is not significant. Thus, ►**Table 7** shows that distress is a significant predictor of adaptive coping among patients diagnosed with reproductive cancer.

Table 7 Summary of multiple regression analysis for variables predicting adaptive coping

Model and predictor variables	B	SEB	B	*t*	R^2	ΔR^2
Model 1						
DSQ Ds	−0.11	0.03	−0.31	−3.60	0.09	0.09
Model 2						
DSQ Ds	−0.05	0.04	−0.14	−1.08	0.11	0.03
DSQ Dp	−0.13	0.07	−0.24	−1.87		
Model 3						
DSQ Ds	−0.03	0.05	−0.08	−0.59	0.12	0.02
DSQ Dp	−0.10	0.08	−0.17	−1.26		
DSQ Ax	−0.07	0.05	−0.17	−1.46		

Abbreviations: DSQ Ax dimensional symptom questionnaire anxiety DSQ Ds, DSQ distress; DSQ Dp, DSQ depression; ΔR^2, R^2change; *B*, unstandardized coefficient; SEB, standardized error of beta; β, standardized coefficient.

* $p < 0.05$.

** $p < 0.01$.

*** $p < 0.001$.

Discussion

Cancer may affect individuals irrespective of their age, gender, and socioeconomic background. This study shows the mean age of reproductive cancer patients is 46.7 years (►**Fig. 3**). In this study, mean values of psychological states demonstrate that there is a strong elevation in the scores of distress and depression (►**Table 1**); the scores of anxiety and somatization are on the moderately higher side among the patients diagnosed with reproductive cancer. A study observed that when diagnosed with cancer, approximately 30% of the patients may suffer extreme psychological distress or other mental conditions.[41] Similar findings are observed in the studies that psychological distress was high and the pandemic had an adverse effect on the mental health of the people.[42] Patients had more difficulty coping with cancer during the pandemic as there is increased concern regarding susceptibility to infection and concerns regarding their cancer treatment outcomes.[43]

In the present research, it is observed from the mean score of different types of coping (►**Table 2**) that seeking emotional support is reported very high (76%), followed by venting (63%), self-distraction (62%), instrumental support (59%), religion (51%), and behavioral disengagement (50%). On the other hand, humor (23%), substance use (25%), and positive reframing (31%) coping strategies are seldom used by patients diagnosed with reproductive cancer. Diverse coping strategies are observed in this study such as venting, which points to giving expression to one's emotions and seeking emotional support for attaining moral support, sympathy, compassion, and care among patients diagnosed with cancer.

In this study, it is observed that more than 60 (50%) people find some peace and solace in following their religious and spiritual beliefs in the process of coping with cancer. Research acknowledges that religion serves as a source of emotional support and spirituality serves as a strong coping mechanism providing spiritual strength and a healing touch to body and mind during cancer.[44] In this study, maladaptive coping is observed highest, and adaptive coping method is the least observed among reproductive cancer patients (►**Table 3**). The correlation matrix (►**Table 4**) demonstrates a significant negative correlation between psychological states and coping methods. A review of related studies demonstrates similar findings supporting the present research that changes owing to a pandemic such as lack of social interaction and support, lifestyle changes, issues in the work front, and added family responsibilities contributed to psychological distress and the manifestation of mental health issues.[45,46]

To summarize, this study observed a significant negative correlation between psychological states and coping in patients diagnosed with reproductive cancer. Predictors of coping are thereby inferred using multiple linear regression analysis (►**Tables 5–67**) that distress and depression are predictors of problem-focused coping; distress and anxiety are predictors of emotion-solving coping; and distress is the predictor of adaptive coping among patients diagnosed with reproductive cancer.

Strengths and Limitations of the Study

There seems to be a sparsity of Indian studies that indicate the statistics related to cancer populations in India, during the pandemic phase. The diverse age of the participants, the inclusion of persons from the rural and urban areas, both men and women, the study conducted during the pandemic, and exploring their challenges are the key strengths of the study. Research explains that psycho-oncology gives insight into taking care of cancer patients, explaining the psychological issues in oncology settings from the communication of diagnosis to treatment and end-of-life care.[47,48] This study explored the psychological states and coping mechanisms of cancer patients during the pandemic, while taking necessary precautions to safeguard their health, and imparted psycho-education and psychosocial support for holistic cancer care.

In this study, as there was no baseline data collected before the onset of the COVID-19 pandemic, and the data collection was done during the pandemic phase, comparison with non-COVID-19 situation was not possible. Hence, whether the findings are attributable to the existent COVID-19 situation is not clear within the scope of the study that becomes a limitation of the study.

The Implication of the Study

It is important to mention that the augmentation of factors such as social support and information from authentic sources, dealing with the economic and financial burden, and changes in the environment and lifestyle owing to the COVID-19 pandemic emphasize the need for supportive psychosocial interventions as per the previous research.[49] The findings explain the adverse effects of the pandemic and possible interventions such as telepsychology and online psychological treatments to decrease the negative effects of the pandemic. Thus, a future direction seen is to expand the scope of the study to an interventional model. Supportive psychosocial interventions to deal with psychological states and better coping are recommended for future research.

Ethical Approval

The study fulfills research ethics and the Helsinki declaration, and approval was taken from the Institutional ethics committee, the University of Hyderabad on 24–2-2022 (UH/IEC/2020/257). Informed consent and participation informed sheet were provided to the participants and complete confidentiality was assured for the study.

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Conflict of Interest

None declared.

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Impact of the COVID-19 Pandemic on the Psychological Well-Being of Health Care Professionals in India

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Abstract

Introduction and Objective Health care professionals (HPs) have been at the forefront facing the pressures and uncertainties of the COVID-19 pandemic, and thus have a higher psychological vulnerability. The incidence of psychological distress, which can negatively affect an HP's work efficiency and long-term well-being, has not been studied in depth in India.

Materials and Methods A multicentric study was conducted using the digital means of communication across Max Healthcare between June and August 2020. HPs in the department of oncology, including doctors, nurses, and other support staff, were invited to voluntarily participate in the self-administered online survey. A total of 87 HPs in oncology (41 doctors, 28 nurses, and 18 in other fronts) were assessed using the 12-item General Health Questionnaire (GHQ-12). Outcome of interest was psychological distress (defined as a GHQ-12 score >15).

Results The overall incidence of psychological distress among HPs in oncology during the COVID-19 pandemic was 17.20%. Significantly higher levels of psychological distress were observed among HPs with a history of psychiatric illness ($p = 0.003$), and among HPs with a work experience of less than 10 years ($p = 0.017$).

Conclusion The COVID-19 pandemic had a significant impact on the psychological well-being of HPs in India. This study implicated the recognition of the psychological well-being of HPs in oncology as an unmet need during the COVID-19 pandemic, further recommending efforts toward increasing accessibility of mental health services for them.

Keywords
- COVID-19
- GHQ-12
- health care professionals
- India
- psychological
- well-being
- oncology

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Introduction

The emergence of a new coronavirus disease, called COVID-19, has recently caused a tremendous public health crisis globally.[1] It has been observed that the pandemic has affected people all over the world socially, mentally, physically, psychologically, and economically.[2] India was hit by the COVID-19 pandemic in the month of March 2020, when a national lockdown was announced, affecting a large part of its population and adversely impacting the health care systems across the country. This led to unexpected challenges and burdens for health care professionals (HPs) in various public and private setups.[3]

In a review by Vizheh,[4] it was observed that during the initial stages of the COVID-19 pandemic, 29% of all hospitalized patients were HPs. It was also reported that HPs were one of the most vulnerable groups across the world during the COVID-19 pandemic.[5] Thombs et al expressed a concern regarding the vulnerability of adequate medical care for all affected persons in need.[6] They further estimated that prolonged restrictions and isolation exacerbated problems like health, psychological well-being, social functioning, and unemployment. It was further predicted that individual and social economic resources would be insufficient in the near future.[6] Doctors had reported a growing concern and discomfort due to lack of personal protective equipment (PPE), and once the frontline staff had started contracting the disease, other workers became potential threats to subsequent patients.[2] One study identified factors such as heavy workload, fear of infection, concern about family, underlying illness, being an only child, and female gender to be contributing to the health care workers' reduced mental health taking a toll on their psychological well-being.[7] Que et al reported that in comparison to the general population, HPs had faced greater pressure from COVID-19, especially those who had been in contact with suspected or confirmed cases, because of higher risks of infection, loss of control, lack of experience in managing the disease, overwork, perceived stigma, lifestyle changes, isolation, and lesser family support.[1] The specificity of psychopathological expressions among medical professionals was reported to be dependent on both individual factors (e.g., age, sex, and the presence of children) and institutional factors (e.g., the length of service, changes to working time, and the availability of PPE).[8]

The mental health concerns in relation to the COVID-19 pandemic in India are more complex due to a larger proportion of socially and economically vulnerable populations (children, geriatric, migrant laborers, etc.), higher burden of preexisting mental illness,[9] more constrained mental health services infrastructure,[10] less penetration of digital mental health solutions, and, above all, the scare created due to tremendous misinformation on social media.[11] All HPs have been identified to be at an increased risk of mental health concerns, especially oncology professionals who are as it is in constant contact with suffering and death.[12] It has also been seen through several data that several HPs working in oncology care showed symptoms of burnout, attributed to work dissatisfaction, work overload, organizational problems, communication problems, and emotional concerns with patients and colleagues.[13] Therefore, we decided to focus only on the oncology HPs of our health care setup to understand the impact of the pandemic on their psychological well-being.

The aim of our study was to understand the psychological distress among HPs in the department of oncology across a group of tertiary hospitals in the private sector in India, during the COVID-19 pandemic. The study's outcome has implications for planning and providing psychological interventions (or therapeutic services) to HPs.

Materials and Methods

Study Design

Setting

This was a prospective multicentric study conducted on HPs in oncology (including doctors, nurses, and other support staff) across seven units of Max Healthcare (MHC), a cluster of tertiary care hospitals in the Delhi National Capital Region (NCR) of North India. All HPs were employees of MHC, aged >18 years who had voluntarily consented to take part in the study.

Instrument

Psychological distress was assessed using the 12-item General Health Questionnaire (GHQ-12).[14] It is a self-administered screening tool that assesses an individual's inability to carry out one's normal healthy functions and the appearance of psychological distress. It has been found to be reliable and valid.[15,16]

The 12 statements (see ►**Appendix A**) were rated on a 4-point scale with a scoring weight of 0 to 3. Thus, the total score was expected to range from 0 to 36. A higher score indicated increased levels of psychological distress and poor general health (scores between 11 and 12: typical; scores >15: evidence of distress).

Although the measuring tool has been validated in three Indian languages (Kannada, Hindi, and Tamil), it was administered in its original English format as the target population was well versed in English.

Conduct of Study

The instrument was self-administered via an online survey. In addition to the 12 statements of GHQ-12, information about the respondent's demographic details, previous history of physical and psychiatric illness, and family circumstances was also collected. The participants were contacted individually via a designated survey link to register responses online, which was distributed through the primary means of digital communication (e-mail addresses, text messages, and WhatsApp). Identifiable information was not collected.

After the first request for participation, two further reminders were sent to all the individual employees and the data were collected between June and August 2020.

Data Analysis

Data analysis was limited to completed questionnaires. The primary outcome of interest was the rate of psychological distress. Factors associated with psychological distress were analyzed using SPSS software (IBM SPSS Statistics for Windows, version 20.0, IBM Corp, Armonk, NY). The correlations between variables (including gender, age range, professional category, marital status, work experience, past history of physical and psychiatric ailments, and presence of a family member older than 70 years) with the desired outcome of interest were calculated. Continuous variables have been presented as median, whereas categorical variables are presented as percentage. Chi-squared test or Fisher's exact test, whichever was applicable, was applied for categorical variables. All tests are two sided and $p < 0.05$ is taken as the level of significance. Further, a multivariate analysis and logistic regression for distress was conducted using the forward conditional method.

Ethics Statement

The study was conducted according to the guidelines of the declaration of Helsinki, and approved by the Institutional Review Board (or Ethics Committee) of Max Super Specialty Hospital, Saket, New Delhi, India (the protocol code was RS/MSSH/DDF/SKT-2/IEC/S-ONCO/20–13 and the date of approval was May 7, 2020).

Results

Response Rate and Respondents

Data were collected from a total of 87 HPs including 41 doctors, 28 nurses, and 18 support staff, comprising 34 males and 53 females, from the Department of Oncology across seven different units of MHC (Delhi-NCR, India). The median age of the participants was 32 years (range: 20–58 years). The demographic distribution and descriptive statistics of the study population are presented in ►**Table 1**.

Psychological Distress and Factors Associated with It

Of the 87 participants, 15 (17.20%) HPs showed the presence of psychological distress (defined as GHQ-12 score >15) during the COVID-19 pandemic. The correlation between the variables and primary outcome of interest (psychological distress) measured by GHQ-12 is also presented in ►**Table 1**. The results of the univariate logistic regression analysis indicated that psychological distress among HPs was associated with a prior history of psychiatric illness (80%, $p = 0.003$), along with HPs with a work experience of less than 10 years (25%, $p = 0.017$). The multivariate logistic regression analysis revealed that a prior history of psychiatric illness is the only significant predictor for distress ($p = 0.003$). Other variables, namely, age, gender, marital status, job description, history of physical illness, or having a family member above the age of 70 years exhibited no significant predictive relationship with psychological distress.

Components of Psychological Distress

Among the various components of GHQ-12 (as shown in ►**Figs. 1** and **2**), the greatest impact was reported on the ability to enjoy normal day-to-day activities (adversely affected in 41.4%), the ability to concentrate (32.2%), the feeling of constantly being under strain during the course of their work (28.7%), and the feelings of unhappiness and depressiveness (26.4%). On the other end, feelings of worthlessness (5.7%), loss of self-confidence (10.3%), and inability to overcome difficulties (11.5%) were found to be significantly increased in a small minority of the respondents, reflecting their resilience.

Table 1 Prevalence of psychological distress among health care professionals and factors associated with it

Variable	Total	Psychological distress		
	$N = 87$	No	Yes	*p*-Value
Age range (y)				
Above 35	29	89.70%	10.30%	0.229
Below 35	58	79.30%	20.70%	
Gender				
Female	53	73.50%	26.50%	0.068
Male	34	88.70%	11.30%	
Marital status				
Married	57	82.50%	17.50%	0.918
Unmarried	30	83.30%	16.70%	
Professional category				
Doctor	41	80.50%	19.50%	0.871
Nurse	28	82.10%	17.90%	
Others	18	88.90%	11.10%	
Work experience (y)				
< 10	56	75.00%	25.00%	0.017
> 10	31	96.70%	3.30%	
Past history of physical ailment				
No	77	83.10%	16.90%	0.681
Yes	10	80.00%	20.00%	
Past history of psychiatric ailment				
No	82	86.60%	13.40%	0.003
Yes	5	20.00%	80.00%	
Family member above >70 y				
No	73	82.20%	17.80%	>0.999
Yes	14	85.70%	14.30%	

Discussion

Our study offers an important understanding regarding the impact of the COVID-19 pandemic on the psychological well-being of HPs working in the department of oncology in India. We used GHQ-12, which has been found to be reliable and valid[15,16] and is one of the most commonly used tools to measure distress in HPs following viral outbreaks.[17] In our study, 17.20% of HPs showed the presence of psychological distress. It was also observed that HPs with a prior history of a psychiatric illness and having a work experience of less than 10 years reported significantly higher levels of psychological distress. There have been various systematic reviews in this area, most of which are from China, which estimate the prevalence of psychological distress among health care workers during the COVID-19 pandemic to be between 13 and35%.[18–20] A study from India,

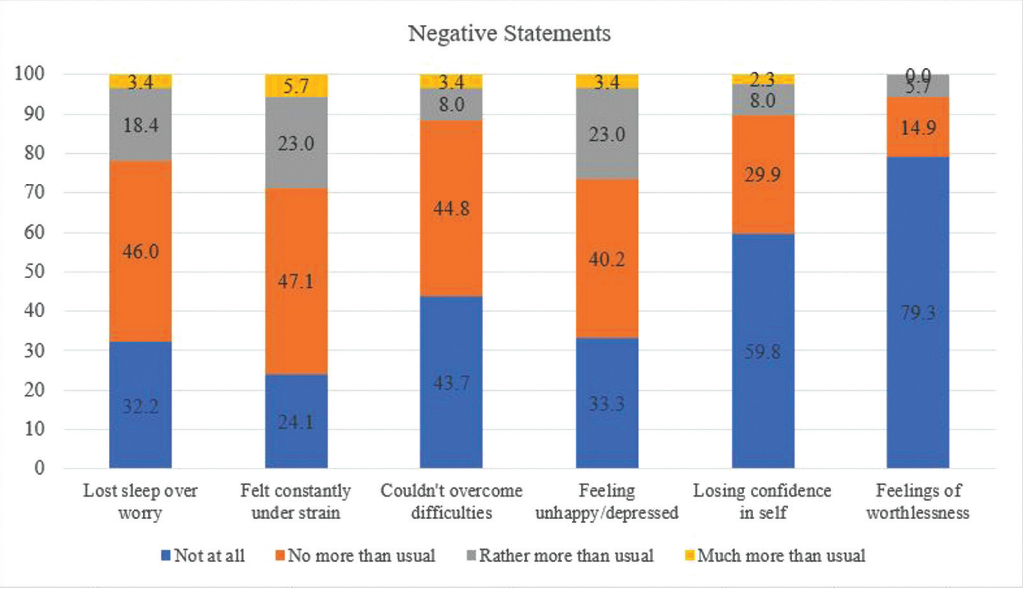

Fig. 1 Components of psychological distress. Negative statements in the 12-item General Health Questionnaire (GHQ-12).

which was part of an international collaborative effort examining the psychological distress among dentists in five countries, reported the overall prevalence of 12.6% with 12.2% among 470 Indian dentists. Existing literature also reports that the COVID-19 pandemic has had an impact on oncology professionals, indicating that 25% of participants (oncology professionals) in one study were at risk of distress (poor well-being).[21] The prevalence of psychological distress among our cohort of 87 HPs (17.20%) is consistent with these observations.

In some other studies, the prevalence of psychological distress was higher in comparison to the findings of this study. A study from India conducted a survey among 265 dental practitioners. The findings revealed that 30.18% participants showed the presence of moderate distress and 65.6% respondents indicated severe distress.[22] One literature review included 148 studies with 159,194 health care workers and pooled prevalence of various factors such as depression, anxiety, fear, burnout, low resilience, and stress. Here, stress was reported to be 36.4%.[23] Another follow-up study to one of the previously cited study[21] highlighted that 33% of the oncology professionals were at risk of poor well-being.[24] This suggests that there is an evident and accumulating effect on oncology HPs' mental health only after a few months of coping with the pandemic-related stress.[25] The study further underscored the long-term nature of the pandemic and its increased burden on oncology HPs, further suggesting long-term impact that requires

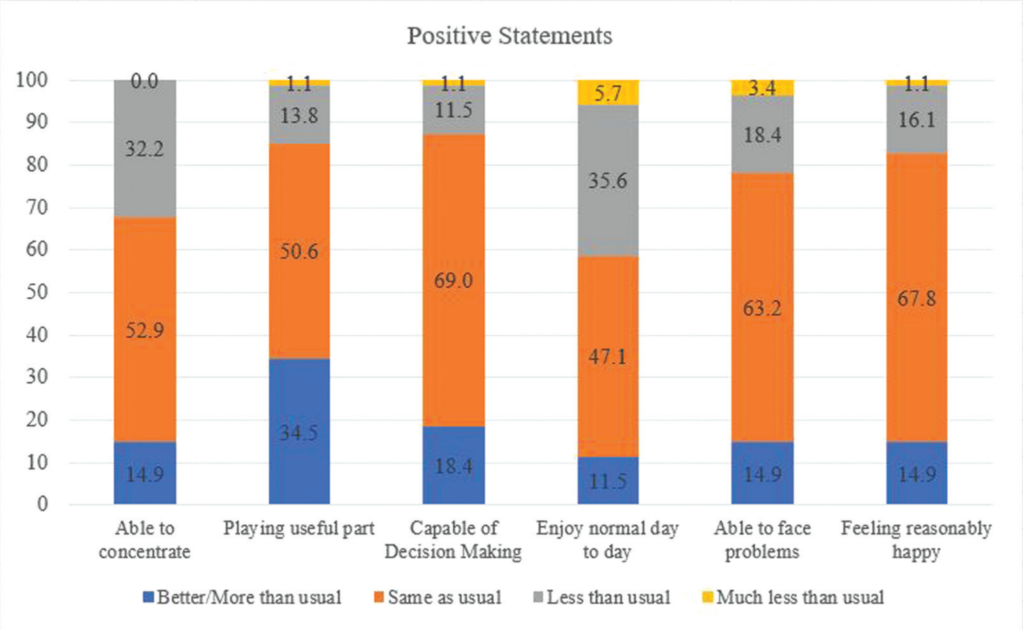

Fig. 2 Components of psychological distress. Positive statements in the 12-item General Health Questionnaire (GHQ-120.

attention and intervention, even after the recession of the pandemic.[25] Some possible reasons for this disparity with our study could be attributed to a larger sample size, period of study, and sampling methodology.

Based on studies on the psychological effects of previous virus outbreaks on health care workers, it was summarized that individual, health care service, and societal factors increase and decrease the risk of adverse psychological outcomes.[17] Multivariate logistic regression analysis of an online cross-sectional study reported that working in a public institution, being employed for less than 5 years, and being overworked were risk factors for developing psychological distress.[26] One study indicated that health care providers who reported to have depression and who reported to have used alcohol, tobacco, and khat in the past 3 months were more likely to experience psychological distress. This study further confirmed that there are increased odds of distress among respondents with underlying depression.[27] One study addressing the emotional concerns of oncology physicians based in the United States reported that anxiety and depression were related to the inability to provide adequate care to patients with cancer.[28] This observation was confirmed in our cohort where it was observed that HPs reporting a prior history of psychiatric illness (13.4%) and work experience of less than 10 years (25%) had a significantly higher prevalence of psychological distress. A limitation of our study was that we did not ask the participants to specify the type of their preexisting psychiatric illness, which would have potentially allowed us to further explore this association.

Due to the pandemic, many HPs were living away from families or were isolated due to the nature and exposure of their jobs. They also had reduced access to any form of domestic help, which further added a burden of maintaining a work–life balance. Many doctors have also faced salary cuts and other financial implications of the lockdown. Junior doctors and nurses (with lesser work experience) were posted in the COVID wards and units, which could have been an added stressor, thereby enhancing psychological distress. Few determinants that may justify these findings could be direct contact with affected patients, forced postings in the COVID wards, stigma against HPs in society, fear of passing on the infection to family members, and lack of training to use the PPE kits, among others, especially in the Indian health care setup.[29]

Other limitations of the study include that data were only collected via an online, self-reported questionnaire in the multivariable study design. It is likely that those with easy access to digital platforms and who are comfortable completing online surveys participated to a greater degree. Social distancing precluded us from distributing and collecting paper forms. The time taken in the design and approval of study allowed us to start collecting data from June 2020, which was approximately 3 months after the onset of the pandemic and the lockdown and may not be representative of the psychological distress experienced by HPs in the immediate days and weeks. Finally, the response rate was low, but our sample size is still comparable to similar studies from India.

Some of the implications of our findings focus on the urgency and the need for health care administrators, advocates, and policymakers to address the psychological wellbeing among HPs during and after the COVID-19 pandemic, and make mental health services easily accessible to them as and when required. There are recognized benefits of coordinated interprofessional team care and subsequently interprofessional education.[30] We created a channel of communication between our HPs and the in-house psychologists and psychiatrists for direct, easy, and free-of-cost access to mental health care. This was conducted through online, telephonic, and face-to-face mediums, and the HPs were given access to mental health professionals according to their comfort and convenience. Confidentiality was ensured and maintained throughout this process. It is suggested that this may be done by altering the assignments and schedules, modifying expectations, and creating mechanisms to offer psychosocial support as needed,[31] along with the addition of assessments of distress and related psychological factors to be implemented if and when the students or trainees are ascending to the frontline or health care setups.[32]

As a training domain, self-care is a spectrum of knowledge, skills, and attitudes including self-reflection and self-awareness, identification and prevention of burnout, appropriate professional boundaries, and grief and bereavement. Evidence indicates that medical HPs receive inadequate self-care training.[33] Some examples of professional self-care techniques can include developing a network of oncology professionals and peers who can share their concerns and techniques of effective coping, and pursuing reflective writing to allow self-expression and catharsis. Organizations can help formalize structures, policies, and procedures to guide team meetings and create a space for healthy and safe personal and professional sharing of sources. In a systematic review, it was reported that interventions conducted with HPs ranged from relaxation techniques, meditation, cognitive behavior therapy (CBT), mobile apps, music therapy, and exercise, to name a few.[34]

Clinical Trial Registration

CTRI number: CTRI/2020/05/025220 (Registered on May 17, 2020); protocol code for Institutional Ethics Committee: RS/MSSH/DDF/SKT-2/IEC/S-ONCO/20–13; and date of approval: May 7, 2020.

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Conflict of Interest

None declared.

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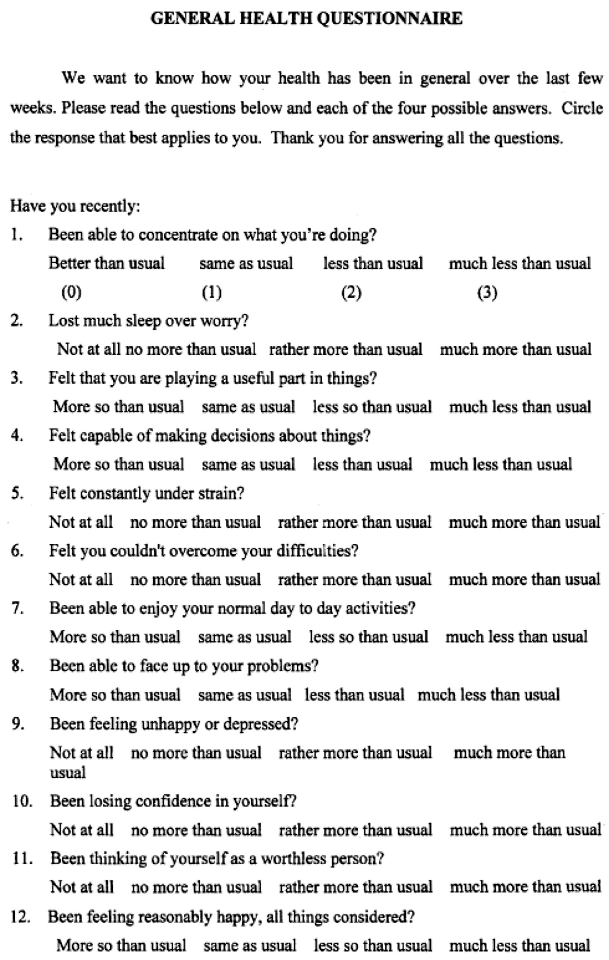

GENERAL HEALTH QUESTIONNAIRE

We want to know how your health has been in general over the last few weeks. Please read the questions below and each of the four possible answers. Circle the response that best applies to you. Thank you for answering all the questions.

Have you recently:

1. Been able to concentrate on what you're doing?

Better than usual	same as usual	less than usual	much less than usual
(0)	(1)	(2)	(3)

2. Lost much sleep over worry?
   Not at all no more than usual rather more than usual much more than usual
3. Felt that you are playing a useful part in things?
   More so than usual same as usual less so than usual much less than usual
4. Felt capable of making decisions about things?
   More so than usual same as usual less than usual much less than usual
5. Felt constantly under strain?
   Not at all no more than usual rather more than usual much more than usual
6. Felt you couldn't overcome your difficulties?
   Not at all no more than usual rather more than usual much more than usual
7. Been able to enjoy your normal day to day activities?
   More so than usual same as usual less so than usual much less than usual
8. Been able to face up to your problems?
   More so than usual same as usual less than usual much less than usual
9. Been feeling unhappy or depressed?
   Not at all no more than usual rather more than usual much more than usual
10. Been losing confidence in yourself?
    Not at all no more than usual rather more than usual much more than usual
11. Been thinking of yourself as a worthless person?
    Not at all no more than usual rather more than usual much more than usual
12. Been feeling reasonably happy, all things considered?
    More so than usual same as usual less so than usual much less than usual

Appendix A: General health questionnaire

Relation between Burnout and Psychosocial Factors in Health Care Providers and Family Caregivers of Patients with Cancer

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Abstract

Introduction Burnout has been widely studied among oncology health care providers such as nurses and doctors. However, it is a less explored but highly prevalent factor in family caregivers of patients with cancer.

Objective The study aimed to understand the construct of burnout among health care providers and family caregivers of patients with cancer, through three objectives: (1) to distinguish burnout between health care providers and family caregivers; (2) to predict burnout based on measurable characteristics, namely, perceived stress, psychological morbidity, well-being, problem-focused coping, emotion-focused coping, and avoidant coping; and (3) to find out the levels of burnout (low, medium, and high) in health care providers and family caregivers.

Materials and Methods It is a cross-sectional study conducted among the health care providers and family caregivers of patients with cancer. The measures used in the study were the Professional Quality of Life scale, 12-Item General Health Questionnaire, Perceived Stress Scale, 5-Item World Health Organization Well-Being Index, Brief COPE inventory, and a sociodemographic details form.

Results The study found a statistically significant difference in the mean burnout of health care providers ($p = 0.027$) and family caregivers. Study variables such as perceived stress and avoidant coping positively predicted burnout, whereas well-being and emotion-focused coping negatively predicted burnout. The study also found that a majority of the participants fell into the category of "medium" level of burnout.

Conclusion While enhancing well-being and employing adaptive coping styles can act as the mitigating factors to burnout, the existence of stress and maladaptive styles of coping can prove counterproductive in dealing with burnout in work environments. This indicates that there is a need for psychosocial interventions to help the medical professionals deal with the burnout.

Keywords
- burnout
- health care providers
- family caregivers
- oncology

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Introduction

Cancer diagnosis has a catastrophic impact on both the professionals providing the care and the family caregivers. Oncology health care providers have high rates of burnout due to exposure to numerous patient deaths, treatment decisions, planning and carrying out treatments, and dealing with high workloads and time pressure, and they experience stress, burnout, and trauma. Family caregivers, on the other hand, have to deal with the emotional and psychological trauma of the diagnosis, stressors associated with the treatment, adjusting their own lives after the diagnosis, and additional caregiver responsibilities.[1–4]

Burnout can be defined as "a state of physical, emotional and mental exhaustion caused by long-term involvement in emotionally demanding situations."[5] The construct has been widely studied over the decades among individuals working in the helping professions. Studies on understanding the effects of burnout on oncology health care providers such as nurses and doctors due to the nature of their jobs have also been common.[6–8] In the case of family caregivers, the most widely studied concept, to understand the exhausting and negative effects of caregiving, has been the study of caregiver burden. Efforts have been made to understand the extent of burnout solely on family caregivers,[9] and studies comparing the effects of burnout on both oncology health care providers and family caregivers together have been sparse. Present study, to the best of our knowledge, is the first in its field to understand burnout in the formal as well as the informal caregivers of patients with cancer. Thus, this study aims to understand the construct of burnout among health care providers and family caregivers of patients with cancer through the following objectives: (1) to distinguish burnout between health care providers and family caregivers; (2) to predict burnout based on measurable characteristics, namely, perceived stress, psychological morbidity, well-being, problem-focused, emotion-focused, and avoidant coping; and (3) to find out the levels of burnout (low, medium, and high) in health care providers and family caregivers. Based on the study findings obtained, recommendations for the development of necessary interventions for both healthcare providers as well as family caregivers to mitigate burnout will be proposed.

Materials and Method

Study Design and Procedure

A cross-sectional study was carried out at a regional cancer center and a corporate cancer hospital located in India for a period of 1 year. The total sample obtained was 309 participants inclusive of health care providers as well as family caregivers of patients with cancer. After taking permissions from the institution ethics committee, the data were collected. Data were collected after obtaining informed consent from the participants ensuring their voluntary participation. The participants were assured regarding their anonymity of participation, confidentiality, and the strict academic use of the data collected. Based on the findings thus obtained, recommendations for the development of necessary interventions for burnout will be designed. Thus, several interventions for the health care providers as well as family caregivers who undergo complexities in psychosocial. After the completion of the study, the participants were debriefed.

The study included five measures, namely, the Professional Quality of Life (ProQOL) scale, Perceived Stress Scale, 12-Item General Health Questionnaire (GHQ-12), 5-Item World Health Organization Well-Being Index, and the Brief COPE inventory. Other details such as the sociodemographic characteristics of the health care providers and family caregivers were also collected.

ProQOL (version 5)[10] is a 5-point Likert scale and has 10 items assigned to each of the three subscales—compassion satisfaction, burnout, and secondary trauma. However, in this study, it was solely used for the measurement of burnout in the participants. It is self-administered and consists of 30 items, originally developed for professionals working in human services. The scale was adopted to be administered among family caregivers of patients with cancer to explore and understand the same. The scale does not yield a composite score. The scale also allows for the categorization of scores, low, average (medium), and high levels, for each category. Scores of 43 or less are categorized as low, scores around 50 as average (medium) level of burnout, and scores of 57 and more as high level of burnout.

The Perceived Stress Scale was used to measure stress. The scale is a 10-item, 4-point Likert scale used to assess participants' perception of stressors in daily life, occurrence of major events in life, and notable changes in coping within the past 1 month.[11]

The GHQ-12, consisting of 12-item and a 4-point Likert scale, was used to measure psychological morbidity.[12]

Well-being was measured by the 5-Item World Health Organization Well-Being Index. It is a 5-item and 6-point Likert scale used to measure participant's positive mood, levels of vitality, and general interests.[13]

Coping was measured with the Brief COPE Inventory. It is a 28-item instrument consisting of 3 broad dimensions, namely, problem-focused, emotion-focused, and avoidant coping, obtaining three separate scores for each subscale.[14] There is no composite score available for this inventory.

Inclusion and Exclusion Criteria

This study recruited health care providers inclusive of doctors and nurses, who have been working in the fields of oncology for more than 1 year, along with family caregivers who have been taking care of patients with cancer over a period of 1 year. Participants with psychological illnesses were excluded from the study.

Primary and Secondary Outcome

Primarily, the study found that there is a significant difference in the burnout experienced by health care professionals and family caregivers, showing that professionals scored higher on burnout when compared with the family caregivers.

The secondary outcome of the study suggests that although family caregivers have scored lower on burnout when compared with the health care professionals, it is important to equally address both the groups and provide suitable interventions to handle the levels of burnout.

Statistical Analysis

Descriptive statistics were carried out to gain an overview of participants' sociodemographic characteristics such as gender, age, marital status, and socioeconomic status. Statistical analyses such as analysis of variance (ANOVA) and analysis of covariance (ANCOVA) were conducted to estimate the variation in the means of burnout in health care providers and family caregivers. Logistic regression analysis and contingency analysis were used to find out the levels of burnout in health care providers and family caregivers. All statistical tests and analyses were carried out using SPSS 21.0 for Windows.

Ethics

The study has been conducted in compliance with the protocol that has gained the approval of the Institutional Ethics Committee of the University of Hyderabad. The approval number as given by ethics committee is "UH/IEC/2018/24" (December 21, 2021). All procedures performed were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Table 1 Sociodemographic details of the health care providers and family caregivers of patients with cancer ($n = 309$)

Variables		Professional caregiver ($n = 153$), n (%)	Family caregiver (n = 156), n (%)
Gender	Male	39 (25.5)	73 (46.8)
	Female	114 (74.5)	83 (53.2)
Age, y	18–27	34 (22.2)	20 (12.9)
	28–37	72 (47.1)	49 (31.6)
	38–47	25 (16.3)	39 (25.2)
	48–57	21 (13.7)	25 (16.1)
	≥58	1 (0.7)	23 (14.2)
Marital status	Unmarried	72 (47.1)	28 (17.9)
	Married	75 (49)	117 (75)
	Separated/ divorced/ widow(er)	6 (3.9)	11 (7.1)
Monthly income, ₹	1,000–7,000	–	105 (67.3)
	8,000–15,000	–	51 (32.7)
	30,000–55,000	17 (11.1)	–
	57,000–80,000	82 (53.6)	–
	≥100,000	54 (35.3)	–

Results

►**Table 1** provides characteristics of the sample. The mean age of the participants was 34.6 years. Most participants were female (63.8%) and were in the age group of 28 to 37 years (39.2%). The majority of the study participants reported to be married (62.1%), and a majority of them were categorized as belonging to the middle social class (43%).

ANOVA was computed to investigate the differences in the burnout experienced by health care providers and family caregivers of patients with cancer. The ANOVA results showed that there exists a statistically significant difference in the mean burnout between health care providers and family caregivers, $F(1, 307) = 4.917$, $p = 0.027$. Health care providers ($M = 53.27$) experienced more burnout when compared with family caregivers ($M = 48.94$).

ANCOVA was carried out to understand the burnout experience in health care professionals and family caregivers of patients with cancer in light of perceived stress, psychological morbidity, well-being, problem-focused coping, emotion-focused coping, and avoidant coping. While both groups of participants (types of caregivers) were taken as categorical independent variables, the covariates were perceived stress, psychological morbidity, well-being, problem-focused coping, emotion-focused coping, and avoidant coping. Levene's test and normality tests were done and assumptions were met. ANCOVA results in ►**Table 2** show a statistically significant difference in the mean burnout between the two groups, when controlled for perceived stress ($F(1, 301) = 40.62$; $p < 0.0.001$), well-being ($F(1, 301) = 13.88$; $p < 0.001$), emotion-focused coping ($F(1, 301) = 20.10$; $p < 0.0.001$), and avoidant coping ($F(1, 301) = 40.62$; $p < 0.001$).

Parametric estimates in ►**Table 3** show a positive relationship between perceived stress ($B = 0.69$, $p < 0.001$) and

Table 2 Analysis of covariance for the dependent variable burnout

Source of variance	SS	df	MS	F
Perceived stress	2,183.15	1	2,183.15	40.62^{***}
Psychological morbidity	60.34	1	60.34	1.12
Well-being	746.39	1	746.39	13.88^{***}
Problem-focused coping	9.72	1	9.72	0.18
Emotion-focused coping	1,080.14	1	1,080.14	20.10^{***}
Avoidant coping	1,193.88	1	1,193.88	22.2^{***}
Type of caregiver	952.91	1	952.91	17.73^{***}
Error	16,177.0	301		

Abbreviations: df, degree of freedom; MS, mean squares; SS, sum of squares.
Note: $R^2 = 0.471$, adjusted $R^2 = 0.459$.
$^{***}p < 0.001$

Table 3 Parameter estimates for the dependent variable burnout

Parameters	B	SE	t
Perceived stress	0.699	0.110	6.3373^{***}
Psychological morbidity	0.132	0.125	1.069
Well-being	−0.098	0.026	-3.727^{***}
Problem-focused coping	0.061	0.142	0.425
Emotion-focused coping	−0.504	0.112	-4.713^{***}
Avoidant coping	0.0872	0.185	4.713^{***}
[Type of caregiver = 0]	4.609	1.095	4.211^{***}
[Type of caregiver = 1]	0a	–	–

Abbreviation: SE, standardized error.
Note: B, unstandardized beta coefficient; t = value of beta.
$^{***}p < 0.001$.

avoidant coping ($B = 0.087$, $p < 0.001$) with burnout. This finding meant that high perceived stress and high avoidant coping predicted high burnout. On the other hand, well-being ($B = -0.98$, $p < 0.001$) and emotion-focused coping ($B = -0.504$, $p < 0.001$) shared a negative relationship with burnout, indicating that higher well-being and emotion-focused coping predicted low burnout and vice versa.

►**Table 4** demonstrates the independent variables that significantly predict the probability of individuals belonging to the "low level of burnout" and the "medium level of burnout" category (i.e., the comparison groups) versus the "high level of burnout" category (i.e., the baseline), conditional on the predictors.

In the "low level of burnout" versus the "high level of burnout" category, the regression slope for the significant predictors, perceived stress, well-being, emotion-focused coping, and avoidant coping is interpreted as follows:

Perceived stress: For an increase of each unit on perceived stress, the odds of a case falling into the "low level of burnout" category (relative to "high level of burnout") decreases by 0.308 units. The odds ratio is 0.735, indicating that with increasing scores on the predictor perceived stress, the odds of falling into the "low level of burnout" category changes by a factor of 0.735. Thus, overall, these results suggest that individuals who score higher on perceived stress are at a lower probability of belonging to the category of "low level of burnout," which means that they are at a greater probability of belonging to the category of "high level of burnout" than individuals who have lower scores of perceived stress ($B = -0.308$, standardized error [SE] = 0.065, $p \leq 0.001$).

Well-being: For an increase of each unit on well-being, the odds of a case falling into the "low level of burnout" category (relative to "high level of burnout") increases by 0.039 units. The odds ratio is 1.039, indicating that with increasing scores on well-being, the odds of belonging in the "low level of burnout" category changes by a factor of 1.039. Thus, overall, these results suggest that individuals who score higher on well-being are at a higher probability/likelihood of falling into the category of "low level of burnout," which means that they are at a lesser risk of falling into the category of "high level of burnout" than individuals who have lower scores of well-being ($B = 0.039$, SE = 0.014; $p < 0.01$).

Table 4 Logistic regression analysis of levels of burnout

		B	SE	Exp(B)	p
Low level of burnout	Perceived stress	−0.308	0.065	0.735	**0.000*****
	Psychological morbidity	−0.041	0.067	0.960	0.541
	Well-being	0.039	0.014	1.039	**0.005****
	Problem-focused coping	0.014	0.070	1.014	0.845
	Emotion-focused coping	0.104	0.055	1.109	**0.050***
	Avoidant coping	−0.211	0.095	0.809	**0.026***
	[caregiving = 0]	−1.668	0.591	0.189	**0.005****
		B	SE	Exp(B)	**Sig.**
Medium level of burnout	Perceived stress	−0.252	0.052	0.777	**0.000*****
	Psychological morbidity	−0.012	0.052	0.988	0.822
	Well-being	0.014	0.011	1.014	0.176
	Problem-focused coping	−0.093	0.054	0.911	0.084
	Emotion-focused coping	0.077	0.044	1.080	0.080
	Avoidant coping	−0.216	0.072	0.805	**0.003****
	[caregiving = 0]	0.002	0.435	1.002	0.996

Abbreviation: SE, standardized error.
Note: B = unstandardized beta coefficient; Exp(B) = odds ratio.
$^{*}p \leq 0.05$. $^{**}p < 0.01$.
$^{***}p < 0.001$.

Emotion-focused coping: The regression slope for emotion-focused coping is interpreted as follows: for an increase of each unit on this variable, the odds of a case falling into the "low level of burnout" category (relative to the "high level of burnout") is predicted to increase by 0.109 units. The odds ratio is 1.109, indicating that with increasing scores on this predictor, the odds of falling in the "low level of burnout" category changes by a factor of 1.109. Thus, overall, these results suggest that individuals who score higher on emotion-focused coping are at a higher probability/likelihood of falling into the category of "low level of burnout," which means that they are at a lesser probability of falling into the category of "high level of burnout" than individuals who have lower scores of emotion-focused coping ($B = 0.104$, SE $= 0.055$; $p < 0.05$).

Avoidant coping: For an increase of each unit on this variable, the odds of a case falling into the "low level of burnout" category (relative to "high level of burnout") is predicted to decrease by 0.211 units. The odds ratio is 0.735, indicating that with increasing scores on avoidant coping, the odds of falling into the "low level of burnout" category changes by a factor of 0.735. Thus, overall, these results suggest that individuals who score higher on avoidant coping are at a lower probability/likelihood of falling into the category of "low level of burnout," which means that they are at a greater probability/likelihood of falling into the category of "high level of burnout" than individuals who have lower scores of avoidant coping ($B = -0.211$, SE $= 0.095$, $p = 0.05$).

In the "medium level of burnout" versus the "high level of burnout" category, the regression slope for the significant predictors, perceived stress, and avoidant coping is interpreted as follows.

Perceived stress: For an increase of each unit on this variable, the odds of a case falling into the "medium level of burnout" category (relative to the "high level of burnout") is predicted to decrease by 0.252 units. The odds ratio is 0.777, indicating that with increasing scores on perceived stress, the odds of falling into the "medium level of burnout" category changes by a factor of 0.777. Thus, overall, these results suggest that individuals who score higher on perceived stress are at a lower probability/likelihood of falling into the category of "medium level of burnout," which means that they are at a greater probability/likelihood of falling into the category of "high level of burnout" than individuals who have lower scores of perceived stress ($B = -0.252$, SE $= 0.052$, $p \leq 0.001$).

Avoidant coping: For an increase of each unit on this variable, the odds of a case falling into the "medium level of burnout" category (relative to the "high level of burnout") is predicted to decrease by 0.216 units. The odds ratio is 0.805, indicating that with increasing scores on this predictor (avoidant coping), the odds of falling into the "low level of burnout" category changes by a factor of 0.805. Thus, overall, these results suggest that individuals who score higher on avoidant coping have a lower probability/likelihood of falling into the category of "medium level of burnout," which means that they are at a greater probability/likelihood of falling into the category of "high level of burnout" than individuals who have lower scores of avoidant coping ($B = -0.216$, SE $= 0.072$, $p \leq 0.01$).

Table 5 Contingency analysis of the levels of burnout

Levels of burnout	Low	Medium	High	Percent of levels
Low	21	36	6	33.3%
Medium	11	128	21	80.0%
High	0	37	49	57.0%
Overall percentage	10.4%	65.0%	24.6%	64.1%

The probability of an individual falling into one of the levels of burnout has been calculated by the contingency analysis. It has also been used to determine which level of burnout is the best predictor of the model. As shown in ►**Table 5**, low levels of burnout were correctly predicted by the model only 33.3% of the time, while medium levels of burnout were correctly predicted by the model 80.0% of the time and high levels of burnout were correctly predicted by the model 57.0% of the time by the model. This shows that the classification was accurate with respect to the medium level of burnout and equally accurate in the high level of burnout. However, in the low level of burnout, it is biased toward the medium level of burnout. Overall, this suggests that the model is more or less well to classify an individual into the level of burnout. Contingency analysis has been carried out as a validation for the above-mentioned logistic regression analysis.

Discussion

The results of the study were threefold: the first aim was to distinguish burnout between health care providers and family caregivers; the second aim was to predict burnout based on measurable characteristics, namely, perceived stress, psychological morbidity, well-being, problem-focused coping, emotion-focused coping, and avoidant coping; and the third aim was to find out the levels of burnout (low, medium, and high) in health care providers and family caregivers of patients with cancer.

The study found a difference between the experience of burnout among the health care providers and family caregivers, thus supporting the first objective. It was seen that health care providers experienced more burnout when compared with family caregivers. This can be explained by the nature of their job, which entails work-related stressors[2] as well as dealing with the emotional exhaustion of patients' pain and death,[3,15,16] when compared with their counterparts, family caregivers.

According to the second and third objectives, it was checked whether there was a difference between the two groups with respect to perceived stress, well-being, emotion-focused coping, and avoidant coping. It was seen that there exists a difference between these two groups as mentioned previously. Perceived stress positively predicted burnout, indicating that individuals who perceived stress experienced more burnout. Therefore, overall, this suggests that individuals who score higher on perceived stress are at a higher probability/likelihood of high level of burnout and less likely to belong to low or medium levels of burnout. This has also been found in previous studies[17] and can also be explained by the concept of burnout, i.e., a phenomenon that emerges due to the prolonged exposure to stress and demanding situations,[18,19] especially in the context of medical field.

Avoidant coping also positively predicted burnout, which showed that individuals who adopted avoidant coping mechanisms to deal with the stressors experienced more burnout. Hence, overall, this suggests that individuals who score higher on avoidant coping are at a higher probability/likelihood of high level of burnout and less likely to belong to low or medium levels of burnout. This finding is in line with the recent research conducted on health care professionals.[20–22] However, it is important to note that this finding was also contrary to previous research that did not find that coping strategies predicted burnout.[23]

Moreover, it was also seen that emotion-focused coping and well-being negatively predicted burnout. This indicates that individuals who increasingly adopted emotion-focused mechanisms to cope were seen to have lower burnout and vice versa. Thus, overall, this suggests that individuals who score higher on emotional-focused coping are at a higher probability/likelihood of low level of burnout and less likely to belong to the high level of burnout category. This was supported by previous research that stated health care professionals use emotion-focused mechanisms to deal with work-related as well as personal situations, such as having an active social life and maintaining a positive disposition to combat burnout.[22,24,25]

Likewise, well-being also predicted burnout negatively, indicating an increased experience of well-being leads to the decreased experience of the burnout and vice versa. Therefore, overall, this suggests that individuals who score higher on well-being are at a higher probability/likelihood of low level of burnout and less likely to belong to high level of burnout.[26]

Conclusion

Major findings of the current study show that health care providers of patients with cancer experience more burnout when compared with family caregivers of patients with cancer. It was also seen that while factors such as perceived stress and avoidant coping predicted and increased the risk of burnout, factors such as well-being and emotion-focused coping decreased the risk of burnout. This indicates a strong need for psychosocial interventions to help the medical professionals deal with the burnout. While their professionalism and regular exposure to all situations may contribute to their strength, the same may also contribute to anticipation and sensitivity to crisis faced by patients and as medical professionals to the challenges. Hence, customized relaxation techniques and stress management programs targeting doctors and nurses and other health professionals are recommended. At the same time, caregivers who are the silent sufferers and do not vent out their psychosocial suffering also need to be paid attention to with suitable psychosocial interventions.

The study included participants from only one state from India; a larger pool will expand the scope of the study. Integrative health team should include not only the health professionals but also family caregivers and other related professionals who can address different aspects of aligned care relevant to the needs of the patients and caregivers. This may minimize the stress both in terms of family caregivers and also health care professionals who get greater support in the health care. Cross-cultural studies comparing the cultural factors leading to the burnout of professionals and family caregivers dealing with patients with cancer are needed to design culture-appropriate interventions to deal with burnout.

Note

The manuscript has been read and approved by all the authors, that the requirements for authorship have been met, and that each author believes that the manuscript represents honest work

Authors' Contributions

D.A. conducted the literature search, data acquisition, data analysis, manuscript preparation, and manuscript editing. G.P. was responsible for the concept, design, and manuscript review. C.R.R. handled the statistical analysis.

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None.

Conflict of Interest

None declared.

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TechCare: Transformative Innovations in Addressing the Psychosocial Challenges of Cancer Care in Kerala, India

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Abstract

As the global burden of cancer continues to escalate, the holistic care of patients demands innovative approaches that extend beyond medical interventions. This article delves into the transformative landscape of cancer care in Kerala, India, focusing on the intersection of technology and psycho-oncology. Examining the role of the state government, Kerala Startup Mission (KSUM), and individual startups and institutions, including Malabar Cancer Institute and Cochin Cancer Research Centre, we explore how technological innovations, telemedicine, and e-health solutions are actively shaping psycho-oncological support. Leveraging on case studies, we identify notable innovations, including artificial intelligence-based cancer screening, personalized treatment plans, and mental health support. The results signify a paradigm shift toward comprehensive, patient-centric cancer care, potentially influencing broader health care strategies. Despite acknowledging regional specificity and potential biases, the study underscores the transformative role of technological entrepreneurship in revolutionizing cancer care, paving avenues for future research for integrating psycho-oncological support in health care policies and startup initiatives. Overall, the article highlights the evolving landscape in Kerala as a beacon for holistic and patient-centric strategies that prioritize mental health alongside medical interventions.

Keywords
- psycho-oncology
- Kerala model of health care
- medical Innovation
- social innovation
- cancer care
- Kerala Startup Mission
- tech-entrepreneurship

Introduction

Cancer, a pervasive global health concern, not only manifests as a physical ailment but also intricately weaves through the sociopsychological and emotional fabric and disproportionately affects individuals and communities. In recent years, the global rates of cancer incidence and mortality have witnessed an upward trajectory, particularly in countries such as India. In 2018, cancer accounted for 5.7% of all deaths in India, making it the country's fifth most common cause of death.[1] The National Cancer Registry Program's data show a steady increase in cancer-related deaths in India, with 770,230 deaths in 2020, 789,202 in 2021, and 808,558 in 2022. It is estimated that about one in nine people in India will experience cancer in their lifetime, with approximately 1,461,427 new cases in 2022.[2,3] Disturbingly, the Indian Council for Medical Research reveal a projected increase in cancer cases to 29.8 million by 2025,[4] emphasizing the urgent need for effective prevention, screening, and treatment strategies.

Amidst these concerns, the state of Kerala emerges as a beacon of hope, establishing itself as a hub for technological innovations and government initiatives to reshape cancer care. Kerala has been in the limelight, witnessing cancer incidences of 135 per 100,000 in 2016, surpassing the

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national incidence rate of 100 per 100,000.[5] Situated on the southwestern coast of India, Kerala has already gained prominence as a successful model of health care.[5] In recent years, the region demonstrated growth and innovation through collaboration between startups and the government agency Kerala Startup Mission (KSUM), attracting national and international recognition.[6] This article highlights Kerala's technological prowess and innovative governance in integrating psychosocial considerations into cancer care. Recognizing the interdependence of technology and psychosocial well-being in comprehensive health care strategies, KSUM, a nodal agency under the state government, fosters a conducive ecosystem for startups, fostering breakthroughs in cancer prevention, screening, and treatment.[7]

Delays in patients' help-seeking are attributed to various factors, including personal, sociocultural, and economic factors. One social determinant that frequently dissuades people from getting cancer treatment is stigma. Cancer stigma negatively impacts patients' physical and mental adjustment to the disease, leading to poor quality of life, feelings of isolation, treatment nonconformity, and avoidance of health care providers. This psychosocial problem affects patients' day-to-day lives, resulting in clinical and social repercussions, thereby intensifying the burden of the disease.[8–13] Simultaneously, issues of accessibility and affordability create disparities in the delivery of care, preventing equitable access to life-saving interventions.

Literature Review

The surge in cancer cases in India necessitates a profound exploration of critical psychosocial factors associated with the disease—primarily, challenges in accessing treatment, affordability, and the overarching issue of stigma.

Exploring cancer-related stigma reveals its pervasive impact on health equity, giving rise to exclusion, rejection, and societal blame. The stigma also leads to fear and shame, which negatively affects people's health and willingness to engage in screening and care services. While research on the correlation between cancer stigma and health outcomes remains limited, compelling studies suggest links to delayed diagnosis, heightened depression, and the attribution of the disease to perceived social norm violations or a "bad personality."[12] Drawing on theoretical foundations, Erving Goffman's exploration of the concept of stigma and its impact on individuals in society[14] and Susan Sontag's cultural and metaphorical perceptions surrounding illnesses[15] provide valuable insights into the understanding of societal perceptions and stigmatization related to health conditions. These perspectives are similar to the experiences of those grappling with cancer.[16] Arthur Kleinman also emphasizes the sociocultural dimensions of illness experiences, underscoring the significance of cultural beliefs and community dynamics.[17] Unveiling the intricacies of stigmatization, shared beliefs, and cultural concepts such as Karma, researchers have identified tangible consequences, including "social isolation, gossip, verbal abuse, diminished marriage prospects, and even physical separation within households," often highlighting the pervasive impact of cancer stigma on both patients and caregivers, uncovering the secondary stigma experienced by the latter.[18,19] Moreover, societal perceptions and cancer-related stigma act as formidable barriers to screening, early diagnosis, and treatment in India, profoundly affecting the overall quality of life for cancer patients.[20]

Looking at the challenges of health care accessibility and affordability, geographical barriers and economic disparities often lead to delays in seeking medical assistance and adversely affect primary, palliative, and survivorship care.[21–23] Sixty-nine percent of India's population lives in rural areas, where access to tertiary cancer centers is severely limited by issues with accommodations, long travel distances, and linguistic and cultural barriers.[24]

Cancer care in India is relatively less expensive compared with developed nations like the United States, but most Indian patients face high costs relative to their annual income. Due to India's skewed wealth distribution 57% of the national income is held by the top 10%, therefore cost of cancer care is miniscule for the creamy layer, while for the majority, even basic cancer care can be catastrophically unaffordable. The complex interplay of government structures, state budget allocations, low health insurance coverage, and a predominantly privatized health care system results in substantial out-of-pocket payments for cancer care even within the framework of existing government-initiated health insurance schemes such as Government of Kerala's Karunya Arogya Suraksha Padhathi (KASP) Cancer Suraksha Scheme and the Central Government**'s** Health Minister's Cancer Patients Fund (HMCPF).[24–27]

However, despite efforts to resolve the issues of accessibility and affordability through free-of-cost cancer screening, tertiary cancer care, patient navigation, free transportation and diagnostic services, rural medical camps, and subsidized medicines and treatment, acceptance remain low even among high-risk groups, highlighting a critical gap in understanding patient preferences, early treatment and screening facilitators, and the multifaceted social barriers and enablers of cancer care.[24,28] In other words, accessibility and affordability are major psychosocial concerns which civil societies and state has been trying to resolve, apparently these efforts has not been fully successful, often due to the lack of emphasis on the third psychosocial factor—cancer stigma, and its influence on societal participation and use of these facilities.[19]

Shifting to a broader health care landscape, the transformative impact of the Internet unfolds, with next-generation networks incorporating sensing capabilities and multimodal information. This encompasses smart medical and mobile devices, collectively known as the Internet of Things (IoT). Simultaneously, exploring large-scale domains the "Omics" paradigm gains prominence. The confluence of the IoT revolution, Omics, and artificial intelligence (AI) emerges as a potent force poised to reshape health care delivery.[29] In envisioning the future, Dr. Eric Topol's revolutionary perspective in "*The Patient Will See You Now: The Future of Medicine is in Your Hands*" envisages a future where the power of smartphones and biosensors shifts authority from doctors to consumers, advocating for the "democratization" of medicine.[30] These technological advancements provide autonomy, ensure that people can readily receive medical advice and support by enabling consultations with health care specialists without requiring actual travel. Digital technology, in particular, empowers patients, increases awareness, and minimizes the stigma attached to receiving cancer treatment, thereby providing privacy and closing the gap in accessing health care.

The literature emphasizes the empowering impact of startups and digital innovations, particularly telemedicine and e-health solutions, ushering in transformative changes and fostering patient-centered approaches in psycho-oncological care. Thus, technology is evolving itself as a solution to the psychosocial issues of accessibility, affordability, and cancer stigma.

As we delve into the multifaceted challenges posed by cancer and the potential impact of technological innovation in health care, this research article endeavors to explore the following;

1. How does Kerala state government and its welfare policies, alongside institutions like KSUM, use technological innovation to address psychosocial challenges in cancer prevention and care?
2. What's the role of Kerala-based startups and institutions in cancer care within the Kerala model of tech-entrepreneurship?
3. What initiatives are taken to mitigate social stigma, increase screening and prevention, improve accessibility and affordability of cancer care, and integrate psycho-oncological perspectives into the health care landscape of Kerala?
4. How effective are these strategies, as observed in policy documents, reports, and programs, in implementing holistic cancer care?

Methodology

Sample Design and Characteristics

The research combines a qualitative case study and an exploratory research design. The study looks into government institutions ($n = 8$), including KSUM, Centre for Biomedical Research, Innovation and Commercialization in Cancer (BRIC), Kerala Medical Technology Consortium (KMTC), Kerala Development Innovation Strategy Council (K-DISC), Centre for Development of Advanced Computing (C-DAC), Centre for Materials and Electronics Technology (C-MET), Malabar Cancer Centre (MCC), and Cochin Cancer Research Centre (CCRC) and startups ($n = 3$) including Sanscan Medtech and Karkinos Pvt Ltd.

Inclusion Criteria

The selection of these cases is grounded in their significant contribution to technological innovations through startups and collaborations with each other toward cancer screening, prevention, and care and presence within the regional geography of Kerala. All startups and institutions involved in technological innovations toward cancer care that were not based in Kerala were excluded.

Procedure

Data collection primarily involves semistructured interviews with key stakeholders ($n = 23$) from the aforementioned entities. Complementing the interview data are an extensive review of pertinent documents such as policy documents, reports, official statements, annual reports, product brochures, and media analyses. The media and document analysis provides a historical context and enhances overall understanding. In addition to interviews and document analysis, direct observations are conducted in relevant contexts. This includes participation in government-sponsored events ($n = 3$), such as CanQuer2019, a 3-day oncology conference on the theme “Technology to eliminate cancer care disparity, HealthTech”; Technology for Better Healthcare Summit 2022; and KMTC Healthcare Summit 2022. Further, visits to company/institute facilities ($n = 5$) were also conducted to gain first-hand insights into collaborative efforts, innovation processes, and organizational dynamics.

Primary and Secondary Outcome

The primary outcome of this study was the examination of the role of key entities in the Kerala startup ecosystem in advancing technological innovations for cancer screening and care. Secondary outcomes include identifying patterns in innovation strategies, challenges, and collaborations, enriched by thematic analysis and a historical context from document analysis and direct observations at relevant events and facilities.

Qualitative Data Analysis

Thematic analysis is applied to identify common themes in the data from literature reviews, government reports, and interviews, focusing on innovation strategies, challenges, and collaborations. Researchers initially familiarized themselves with the data, coded to label key concepts related to cancer care, government initiatives, financial support mechanisms, and technological innovation, and refined preliminary themes through iterative discussions. These themes are then defined, named, and mapped onto research objectives, providing insights into the study's questions and facilitating interpretation.

Results

Cancer poses a significant health challenge, and the state of Kerala has responded with comprehensive government initiatives to ease the burden on patients and ensure access to essential treatments. These initiatives, characterized by financial aid and support mechanisms, underscore the government's dedication to enhancing cancer care in the region.

Kerala's Cancer Control Program: A Holistic Model

Kerala's cancer control program, initiated in 1988, is a robust and adaptive model addressing multifaceted challenges in cancer care. The program's emphasis on primary prevention has proven effective. Another crucial aspect tackling the issue of accessibility is early detection, facilitated by village-level volunteers, screening camps, and the establishment of "*Early Cancer Detection Centres*," particularly in rural areas. District-level cancer control societies integrate these efforts into the broader health infrastructure, ensuring a comprehensive and sustained approach to early diagnosis and intervention. Human resource development is a cornerstone, with the Regional Cancer Centre (RCC) conducting various training programs for health care professionals. The RCC's role extends to cancer registration, providing essential data for shaping program strategies and evaluating outcomes. The RCC in Kerala demonstrates holistic patient care by offering a free food scheme for below poverty line patients and operating a free medicine bank. These initiatives provide nutritional support and essential medications, including chemotherapy drugs, at no cost, relying on contributions from well-wishers to overcome financial constraints for cancer patients.[31]

The "*Kerala Cancer Care Grid* (KCCG)," a collaborative network encompassing cancer care facilities, plays a vital role in the state's cancer prevention efforts. Entrusted to the RCC, the KCCG contributes significantly to an inclusive cancer prevention and control program aligned with the *Kerala Cancer Control Strategy* (2017–2030).[32] It ensures equitable access to affordable cancer detection and treatment within a 50-km radius of individuals' residences, emphasizing inclusivity. Kerala's cancer control efforts extend beyond clinical interventions. Palliative care, initiated in 1986 and provided as part of the grid, showcases the state's commitment to addressing the holistic needs of cancer patients. Palliative care units, home visit programs, and initiatives to make pain relief more accessible reflect a compassionate and patient-centric approach.[22] This approach not only provides accessibility and affordable care, but tackles the issue of cancer stigma by encouraging societal participation in its activities.

Additionally, unique initiatives like the "*Cancer Care for Life*" insurance program, launched in 1986, have further democratized access to cancer care by providing financial assistance. This innovative insurance model, entailing a one-time payment for a lifetime of coverage, has benefited thousands, demonstrating a commitment to financial inclusivity. Kerala's cancer control program is a comprehensive, community-driven model characterized by preventive measures, early detection strategies, human resource development, and a compassionate approach to patient care. The integration of these components, coupled with political will and community involvement, underscores the program's success and positions it as a valuable blueprint for cancer control in developing societies.[31]

Government Financial Aid

Kerala has instituted a series of comprehensive initiatives to support cancer patients. Chief Minister's Distress Relief Fund, Cancer Suraksha Scheme, KASP, Sukrutham Scheme, and Comprehensive Health Insurance Scheme Plus provide financial assistance and subsidized treatment for cancer patients.[33] These initiatives collectively demonstrate Kerala's strategic and multifaceted approach to addressing financial barriers, ensuring affordability, and providing support for emergencies and vulnerable demographics in the realm of cancer care.

Role of Technological Innovation in Cancer Care and Support in Kerala

KSUM has emerged as a pivotal force in fostering innovation and support for startups contributing to the health care sector. The third annual symposium on "Technology to eliminate cancer care disparity," organized by the *CCRC* and KSUM in 2022,[34] exemplifies the state government's commitment to bringing new technologies to grassroots levels, thereby minimizing disparities in cancer care. The symposium facilitated discussions on leveraging technology for improved cancer care outcomes, patient education, and effective linkages between clinicians and startups.

One notable program supported by KSUM is the BRIC, an incubation program in Kochi that intends to reduce cancer deaths through technology-based, socially impactful startups. Furthermore, KSUM's collaboration with the MCC through a memorandum of understanding aims to establish a cancer care startup ecosystem in the state. This collaborative effort emphasizes the establishment of a medical incubator for cancer research, fostering cross-functional innovation. The incubator, situated at the Kerala Technology Innovation Zone, Kinfra Hi-Tech Park, Kalamassery, seeks to bring together researchers and startups to develop solutions for early cancer detection, exemplifying a holistic approach to cancer care.[35]

Startups incubated or nurtured by KSUM, such as *Sanscan* and *Karkinos*, showcase significant advancements in cancer care. Sanscan Medtech and its innovative OralScan are the first multimodal image-capturing devices that use multispectral imaging technology at their core for noninvasive and real-time screening of oral cancer and biopsy guidance. Their proprietary software, Sascan developed to operate OralScan, is intuitive and easy to use. The service provides higher accuracy and lower per-patient cost, thereby tackling the concern of affordability of cancer screening. This encourages large-scale adoption and helps save millions of lives every year. The startup won the National Startup Awards 2021. The ease of application and affordability of the service offered by the startup is a solution to the major challenges of cancer prevention in India.[36]

Similarly, Karkinos, another startup nurtured by KSUM, has focused on developing personalized cancer care solutions and offer psychosocial care to cancer patients. They have been recognized by the National Health Authority for their exceptional contribution to the Ayushman Bharat Digital Mission.[37] Their platform employs AI to tailor treatment plans based on individual patient profiles. Recognizing the psychosocial challenges associated with cancer, Karkinos integrates features for mental health support, offering in-app resources for coping with emotional distress, connecting users with mental health professionals, and fostering a supportive online community. The results highlight instances where cancer patients utilizing Karkinos' mental health features reporting increased resilience, improved emotional well-being, and a sense of empowerment throughout their treatment journey.

Moreover, collaborations between research institutions like the C-MET, C-DAC, and MCC have resulted in groundbreaking innovations. Notably, a wearable screening device developed by Ms. A. Seema, a scientist at C-MET, for early breast cancer detection has received national recognition.[38] This innovative device utilizes highly sensitive thermal sensors to detect temperature variations caused by cancer cells, providing a noninvasive and user-friendly alternative to traditional mammography. Clinical trials have shown results comparable to standard diagnostic tools like mammograms, ultrasounds, and computed tomography scans, addressing challenges in breast cancer screening in India. This portable, affordable, and easy-to-use diagnostic tool has the potential to reduce the stigma of cancer screening, by getting the device to the doorsteps of common people. The Accredited Social Health Activist (ASHA) workers (ASHA is a health activist in the community who will create awareness on health and its social determinants and act as interface between the community and the public health system) taking the lead to introduce it aim to reduce the stigma and emotional concerns of going to clinics and laboratories for mammograms.

The collaboration of KSUM with K-DISC and KMTC has brought commendable results. Further, this collaboration also known as the *KMTC* aims to establish Kerala as a medical device and technology hub, fostering innovation, research and development, technology development, and manufacturing through a "Beyond Cluster" model that encourages collaboration and natural development. It brings together key stakeholders in research and development, academia, health care, MedTech companies, startups, and the government in bridging the gaps and empowering individuals and institutions to foster the growth of MedTech in the state. K-DISC is the Kerala Government's nodal agency to facilitate Kerala's transition to the knowledge economy apart from making Kerala an innovation hub.[33] In collaboration, these institutions have developed an AI-based system for automated cervical cancer screening using liquid-based cytology, aiming to streamline pathologists' work and improve case handling. The cervical cancer screening via Pap smear analysis is performed in the form of health care camps in the rural parts of the state by K-DISC trying to resolve the issues of accessibility and affordability.

Further, along with their technology partner Evelabs Private Limited, they use IoT, a technology component employed to create Dripo. This simple, portable, connected infusion monitor is helping health practitioners to set infusion rates accurately and monitor them from anywhere. This project is in trial at the MCC. They are also in the initial stages of developing an e-health portal, a single access point for disseminating all information using a multilingual AI chatbot with voice communication capabilities.[33]

Similarly, "I CAN" app developed by Dr. Manu, a cancer survivor and assistant professor at Cochin University of Science and Technology (CUSAT), under the 2-lakh seed money of the CUSAT project titled "Development of Gamified Health Care solutions of patients suffering from cancer," features game elements such as points, badges leaderboards, storytelling, etc. to help patients interact with the experiences of other patients and survivors and thereby maintain a positive attitude while undergoing treatment.[39]

In conclusion, government-supervised approaches of KSUM foster innovation in cancer care through technological advancements, incubation programs, collaborative partnerships, and startup support, aiming to revolutionize cancer care and addressing challenges like affordability, accessibility, and stigma.

Discussion

The results highlight Kerala's commendable efforts in initiating a transformative approach in cancer care, encompassing a multifaceted approach that includes government initiatives, financial aid, and technological innovations. Examining the possible impacts of these results, it becomes evident that the comprehensive cancer control program and financial aid schemes could significantly alleviate the burden on patients, particularly those from economically vulnerable backgrounds. The emphasis on primary prevention, early detection, and the inclusive KCCG implies that individuals might have better access to timely and affordable cancer detection and treatment within their vicinity, ultimately improving health outcomes.

These results translate into tangible benefits in the day-to-day lives of potential patients and survivors. The financial aid initiatives, such as the HMCPF and the KASP, provide substantial assistance, addressing economic barriers to cancer care. For survivors, the on-going support, exemplified by initiatives for rehabilitation through apps like I CAN, suggests a sustained commitment to holistic patient care, potentially easing the challenges faced during and after treatment.

These results carry implications for various stakeholders. For patients and their families, the financial aid programs mean reduced financial stress, increased accessibility to essential treatments, and improved overall well-being. The government's role in initiating and sustaining these programs signifies a commitment to public health, potentially fostering trust and satisfaction among citizens. Hospitals and health care professionals, particularly through the collaborative Cancer Care Startup Ecosystem, stand to benefit from technological innovations that enhance early detection and personalized treatment plans, thereby improving the quality of care.

Furthermore, the new understanding derived from these results holds promise for advancing psycho-oncological support for potential cancer patients and survivors in Kerala and beyond. The recognition of the psychosocial challenges associated with cancer, as exemplified by the startups like Karkinos and the app I CAN, introduces a paradigm shift in cancer care. Tailoring treatment plans based on individual patient profiles and integrating features for mental health support signifies a holistic approach that acknowledges patients' emotional well-being. This could lead to improved coping mechanisms, increased resilience, and a sense of empowerment among cancer survivors. The collaborative efforts between research institutions and startups, as seen in projects like Dripo and the cancer screening tool by C-MET, also indicate a focus on patient-centric technologies that can enhance the overall cancer care experience. These collaborative efforts initiated with government support increases its acceptance within the public and are a solution to the significant concern of cancer-related stigma. Overall, the Government of Kerala and its welfare policies for improving the lives of the people of the state have come into play in initiating, mentoring, and nurturing various programs to provide technological innovation in medical and psychosocial cancer care.

Conclusion

The intersection of technology and psycho-oncology holds immense promise in revolutionizing cancer care potentially impacting patients, survivors, and various stakeholders. Incorporating telemedicine and e-health solutions has demonstrated tangible benefits in providing accessible and personalized psycho-oncological support. Despite challenges related to stigma and resource constraints, the opportunities for improvement through awareness campaigns, training programs, and collaborative initiatives are substantial. The article highlights the transformative role of technological entrepreneurship in cancer care within Kerala, India, focusing on initiatives led by KSUM and its collaborations with various startups and governmental institutions, exemplifying innovations in early cancer detection and integrated psycho-oncological support. While showcasing notable successes, the study acknowledges limitations, including potential bias in representation and regional specificity. Future research and innovation in cancer care could improve psychosocial support, scalability, and sustainability through tele-medicine and e-health solutions and reduce cancer stigma through targeted awareness campaigns and training programs. This could improve access to timely diagnosis and treatment, reduce financial burden, and enhance patient quality of life. However, replicating these advancements in other states may face challenges like resource constraints, cultural variations, policy differences, and technological infrastructure disparities, necessitating tailored strategies and interstate collaboration.

Authors' Contributions

All authors contributed to the study's conception and design material preparation, data collection, and analysis of the manuscript. All authors commented on all previous versions of the manuscript. All authors read and approved the final manuscript.

Ethical Approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee (Institutional Ethics Committee (IEC), IIT Hyderabad (IITH/IEC/2021/12/13)) and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Patients' Consent

Informed consent was obtained from all study participants.

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Conflict of Interest

None declared.

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Unmet Needs of Oral Cancer Survivors in India: A Perspective

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Abstract

Oral cancer is one of the predominant forms of cancer that alters the livelihood of survivors. They can have many unmet needs. However, very little research has been done on this topic, especially in India. This commentary piece discusses what unmet needs could mean, how the disease culminates differently and creates different realities, how the research and policymaking have been done and how it could be improved.

Keywords
- oral cancer
- unmet needs
- psycho-oncology

Oral cancer is a chronic disease with risks of fatality, and it requires patients to undergo operations many times leaving the patients with limited functionality. Because of the nature of the disease, the difficult treatment regime, and the treatment outcomes, patients face “psychological morbidity” because of the functional deficits. In the first year of treatment post-diagnosis, emotional functioning is at its lowest.[1] To cope with the changes, patients adapt many coping mechanisms. Those mechanisms are denial, projecting themselves as someone else, repression or variations like suppression or regression.[2–4]

This combined psychological and physiological deficit leaves patients with increased needs for their day-to-day functioning. These could be emotional needs, financial needs, information needs, etc. Whether the needs are met depends on the intersectionality of the needs and the factors that affect those certain needs. It is estimated that around 90% of newly diagnosed cancer patients experience unmet needs.[5] Although unmet needs as a concept have been a part of the larger international psycho-oncology sphere, there has not been a working definition for unmet needs. For deliberating further research and understanding the associated concepts, a working definition of unmet needs is necessary for cancer research. Here we can define unmet needs as those needs that a person has not been able to satisfy yet. The needs shall correspond to all the aspects that may arise from the disease that the person has or had.

This is even more necessary in India as oral cancer puts a lot of burden on the healthcare delivery systems as it is the most common form of cancer for men in India.[6] India accounts for one-third of the global burden for oral cancer.[7] Adding to that, very little is known regarding the unique needs that oral cancer survivors might have. With treatment regimes including processes like chemotherapy, surgical resection of the buccal cavity, and/or radiation therapy, patients and survivors often experience toxicity because of the treatment and are often distressed about changed appearance and functioning that includes difficulty eating, drinking, and speaking.[5]

More importantly, in India, the nature of oral cancer is different as cancers caused by smokeless tobacco override smokable tobacco. Cancers of gingival and buccal mucosa are common because of the habit of placing the tobacco quid in the oral cavity, while in the west, cancer of the tongue or floor mouth is more common.[8] To understand such a nuanced phenomenon, culturally sensitive tools need to be used in India. For carrying out surveys, there exists validated questionnaires like Health-Related Quality of Life (HRQoL), European Organization for Research and Treatment of Cancer (EORTC), Cancer Needs Questionnaire – Short Form (CNQ-SF), and Cancer Survivors Unmet Needs (CaSUN).[9–12] Of these, CaSUN is the most culturally fluid questionnaire. This questionnaire having 42 questions is divided into four broad sections named “information and medical care issues,”

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"quality of life," "emotional and relationship issues," and "impact cancer of cancer on your life perspective." Through the questions, the major needs of the sample can be quantified. The confusion associated with the use of questionnaires like HRQoL is the absolutist approach in the adaptation of these in contexts where they may not fit well; this may skew the data. For identifying context-specific problems, culturally appropriate tools need to be developed.

Existing literature shows that most needs fall under the psychological domain. Thus, future studies could be performed focusing specifically on emotional needs or similar cross-sectional studies could be performed to refine the data. However, the gap in literature so far is the lack of an understanding of what each of these unmet needs is. In the case of "emotional needs," there is no clear definition of emotional needs demarcating what constitutes emotional needs. If further research on this area is to be based on the existing literature, what constitutes emotional needs is open for vast interpretation and needs to be defined. The CaSUN, how much culturally sensitive it may be, does not contain emotional needs specifically and does not define the four major categories of needs that the questionnaire constitutes. This asks for the development of more appropriate tools for research on unmet needs and a greater magnitude of research on the same. Another peculiar set of needs which might persist for any chronic disease is communication needs. In a study performed in Taiwan, health information needs were at the top.[13] In the Hyderabad-based study as well, the following emotional needs were interpersonal communication needs and medical information needs.[8] Information sharing is mostly based on communication regarding the disease and the care regime. For interpersonal communication needs, tailored counseling is needed based on the subjective experience of the patients. Regarding information communication needs, the DOTS program is a landmark example of using messaging technology efficiently to manage the disease. Instant messages acted as reminders for patients to get their medicines and provide information regularly. Instant messaging technology made patients adhere to the treatment regimen. Many patients used their mobile phones to call healthcare providers regarding doubts, symptoms, treatment, and diet.[14] Information needs and communication needs should not be confused with each other. The absence of information will fall under the domain of information needs, while the information being provided in an unfamiliar language or the information provided with the use of jargon would fall under the domain of communication needs.

Especially in the last 7 years, there has been a lack of literature on unmet needs. Even the oral cancer management guidelines prepared by the Indian Council of Medical Research (ICMR) rely heavily on outdated literature and also foreign literature that might not be suitable for the Indian scenario.[14] This top-down approach of implementing Western research and healthcare models in developing countries is quite apparent across the global south owing to the global north having hegemony in public health research and global health outreach programs. This can be backed up by accounts of Julie Livingston in her book "Improvising Medicine: An African Oncology Ward in an Emerging Cancer Epidemic,"[15] and China Mills in her book, "Decolonizing Global Mental Health: The Psychiatrization of the Majority World."[16]

Additionally, India has put in place practical frameworks for the prevention and treatment of cancer, but the research has been preliminarily oriented toward prevention. In that regard, this lack of research on the post-treatment phase is a preclusion for the state machine to make policies accordingly. The need for state-led research and intervention is heightened as under the "minimum government and maximum governance" idea, the state has moved shifted itself from Fabian socialism to extreme liberalism by reducing government spending. Along with this, increased privatization leaves the healthcare industry at the behest of private players.[17] Insurance policies like Ayushman Bharat Yojana only act as a monetary intervention after the disease is acquired. Beyond that, the management of the disease is up to the care providers. Since no qualitative research has been done on this topic, there is great scope for qualitative research to add valuable information about the needs that oral cancer survivors have in India. Especially in India, qualitative and mixed methods would better capture the cultural and social nuances and add context to the problem to better devise policies. This is because most validated questionnaires used are appropriated for the Western context that would skew the data. But by using a qualitative approach like Interpretative Phenomenological Analysis (IPA), lived experiences of patients with the disease can be tapped into. Or else, if the surveys could be followed by interviews, contextual understanding of factors constituting the surveys can be probed. This will help us better evaluate the problems as the understanding of the disease varies from culture to culture. The same applies to meaning factors like "quality of life" or "best healthcare facility." These things might mean differently to different cultures, communities, and individuals.

Given the fact that tobacco is being consumed in different forms and is a part of the sociocultural milieu in India,[18] culturally appropriate solutions have to be devised. Research on the unmet needs of survivors must be done to specify the needs of oral cancer survivors in India, specific to the context. A more culturally sensitive questionnaire must be validated for more refined empirical research in this area. Most importantly, research on oral cancer survivors would provide solutions that will be completing the whole cancer care regime. Other than spending on more research and putting new systems in place, existing resources need to be utilized without putting an additional burden on these resources. In India where communication needs are the second most unmet need according to a study by Varma et al,[8] using automated messaging services to deliver regular information to cancer patients and survivors could be one efficient solution. Tacit knowledge of doctors, nurses, and caregivers and their experience of treating oral cancer patients and dealing with their needs can be recorded to add to the existing knowledge to refine the quality of care. Moving further, along with policy reviews and research on unmet needs of oral cancer survivors, existing resources of knowledge and tools of care need to be tapped into.

Conflict of Interest

None declared.

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The Conundrum of the Cancer Burden and Disparity in Cancer Care Delivery in Northeast India, with Special Reference to Nagaland

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Introduction

Cancer is a leading contributor to mortality worldwide with approximately nine million deaths in 2020.[1] India accounted for an estimated 7% of cancer cases worldwide with common cancer sites in the breast (14%), lip, oral cavity (10%), and the cervix uteri (9%).[2] Further, the highest estimated mortality rates were due to cancers of the lip, oral cavity (13%), lung (11%), and esophagus (8%).[2]

India has a diverse sociocultural population with unique habits and dietary practices; the incidence of cancers varies geographically due to the interplay of the genetic determinants and environmental factors.[3] The Northeast (NE) region[i] lies on the Eastern border of India and is inhabited by indigenous communities distinctive by a complexed transition zone of cultural, ethnic, religious, and linguistic diversity.[4] Further, these populations share their genomic pool with the southeastern region of China where nasopharyngeal carcinoma (NPC) is common. Comparatively, the incidence of NPC is higher in the NE region than in the rest of country.[5] Furthermore, there are higher incidences of specific types of cancer, such as the departure in the leading cancer site among males from the NE region to the rest of India (ROI).[6] Cancer of the esophagus is the common cancer site in the NE region compared to lip and oral cancer in ROI.[6]

Given the high incidence of cancer in the NE region with distinct clinical presentation compared to the rest of the county, this article highlights issues on cancer burden and the disparity in the cancer care delivery, and discusses ways to address the same.

Cancer Burden in Northeast India

The NE region is the cancer hub of India, with the highest incidence of adult cancers of the upper aerodigestive tract[ii] (UADT) among both sexes worldwide.[7–9] The highest cancer incidence from the NE region is from Kamrup Urban District in Assam, with the cancer of the esophagus being the most common among both the sexes (28.1% in males vs. 39.3% in females).[7,9] The major contributors to UADT are related to the consumption of tobacco—oral or smoking—alcohol, food habits such as consumption of betel quid, smoked meat, low intake of fruits, infection with Epstein–Barr virus, and poorly ventilated houses.[7–9] Reporting on tobacco consumption among the patients diagnosed with UADT, Kataki et al highlighted that 82% of the patients had tobacco habits, with male patients consuming more than female patients (88.1 vs. 63.2%).[8] To put things in perspective, the median age for esophageal cancer among males is 56 years in the NE region compared to 62 years in the ROI.[6] Similarly, the onset of breast cancer is earlier among females from the NE (47 years) than in the ROI (54 years) due to genetic predisposition and high prevalence of triple-negative breast cancer.[6,10]

Apart from cancers of the UADT, the unique sociocultural elements of the NE region also contribute to site-specific cancers. The cancer of the cervix was the leading cancer site for females in Nagaland, Mizoram, Arunachal Pradesh, and Tripura.[9] Despite the known risk factor of infection with HPV-16[iii] and HPV-18 for the cancer of the cervix, it is implied that the causal factor is multifaceted given the resource-constrained setting to receive timely medical care. The state of Arunachal Pradesh had the highest alcohol

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[i] Northeast region of India includes the state of Arunachal Pradesh, Assam, Manipur, Meghalaya, Mizoram, Nagaland, Sikkim, and Tripura. Further, the name is also interchangeably used as Northeast or NE or NE region throughout the article.

[ii] Cancers of the upper aerodigestive tract include the lip, tongue, mouth, pharynx, larynx, and the esophagus.

[iii] HPV is an acronym for human papilloma virus.

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consumption in the country, leading to the most number of liver cancer cases in the NE region.[9] The cancers of the stomach were found to be highest in the state of Mizoram and attributed to cultural food habits such as the consumption of smoked meat and fish, fermented pork fat, and the use of alkali in food.[9] Similarly, given the geographical location of Assam with the presence of waterbodies (e.g., Brahmaputra), the incidence of cancer of the gall bladder was the highest in the NE region. These were attributed to the presence of cadmium, iron, and lead in the local waterbodies, pesticides, and adulterants in mustard cooking oil.[9]

Systemic and Infrastructural Challenges to Cancer Care in Northeast India

On a systemic level, Ngaihte et al reported that the NE states have inadequate hospitals to cater to the region's high incidence of cancer patients.[11] They highlighted that the number of cancer-treating hospitals in a given state did not equate to seeking treatment in the same. Similarly, the lack of trained medical professionals and services drove patients diagnosed with cancer to seek medical treatment out of state. For instance, the states of Arunachal Pradesh, Manipur, Sikkim, and Tripura have only one cancer-treating hospital, each with very few radiotherapy facilities.[12] It was estimated that 5% and 42% of the patients from Sikkim and Nagaland seek treatment from within the NE region, respectively. Further, 95% of the patients from Sikkim avail treatment from outside the NE region as compared to 58% from Nagaland.[6] The ramification of poor infrastructures is such that there are delayed diagnosis and treatment, early mortality from treatable cancers, and out-of-pocket expenditure (OOPE).[6,9,13]

The Burden of Out-of-Pocket Expenditure in Cancer Treatment

Given the poor infrastructure, patients have to avail out-of-state treatment, resulting in expensive OOPE. In India, the mean monthly OOPE in the year 2017 to 2018, for patients diagnosed with cancer, was Rs 6,549 and Rs 8,811 for inpatient and outpatient care, respectively.[13] The NE region had the highest monthly OOPE in inpatient care at Rs 11,105, followed by South India at Rs 9,834. Further, the healthcare burden was highest for patients opting for private hospitals (58%) to public hospitals (63%), with patients from the South and NE regions reporting the highest from outpatient visits.[13] This expenditure weighs heavily on the families too. For an individual diagnosed with cancer, a family's financial support plays an important role in the continuity of cancer care. For instance, most of the patients had to depend on their earnings and savings to pay for health services. Additionally, to pay for the inpatient care, the patients and their family had to borrow from others or sell their possessions.[13]

With the roll-out of the world's largest comprehensive national health insurance scheme (Ayushman Bharat—Pradhan Mantri Jan Arogya Yojana) in 2018 for the disadvantaged socioeconomic population of the country, accessibility to healthcare services is made available. This health insurance scheme covers secondary and tertiary care hospitalization at Rs 5 lakhs per family per year in empaneled private and public healthcare services.[14] Presently, cancer schemes such as the Chief Minister's Free Cancer Chemotherapy Scheme by the state government of Arunachal Pradesh provide its residents with free consultation and medicines worth Rs 10 lakhs per patient in a year. The Government of Tripura provides a pension scheme for cancer patients of Rs 600 per month. As part of the Assam Arogya Nidhi, the Assam government covers cancer treatment, such as chemotherapy and radiation, for families below the poverty line by providing financial assistance up to Rs 1.5 lakhs.[15–17] However, other NE states need to step up and allocate funds for cancer treatment to lessen the financial burden. Further, patients with health insurance also face challenges when the high cost of cancer care exceeds the limit the insurance provider gives.[13] Additionally, besides the medical expenses of the patient, the primary family caregivers also have untold nonmedical expenditures related to travel, food, and accommodation, which are not covered by health insurance plan and incurred more if the treatment is availed out of town. Parallel to the fund allocation, there is a need to focus on early prevention and screening interventions as cancers with high incidence and mortality, such as the oral, cervix uteri, and the breast, are preventable through early detection.[18]

Early Prevention and Screening Interventions to Reduce the Cancer Burden

Low health literacy is associated with limited awareness about cancer screening, the lack of desire for screening, difficulty in understanding screening guidelines, perceived barriers in accessing and navigating the healthcare system, and difficulty in treatment decision-making.[19,20] A study from the NE region reported that despite the high incidence of tobacco-related cancer, almost half (41%) of the participants were unaware of oral, mouth, or tongue cancer. Further, awareness of cancer screening was also low (34%).[18]

The National Family Health Survey (NFHS-5; 2019-2020) found that Assam, Nagaland, and Tripura had the lowest cervical examination within the NE region.[21] For breast examination, attendance was lowest in Sikkim, Nagaland, and Arunachal Pradesh.[21,22] Assam, Nagaland, and Meghalaya recorded the lowest for oral cavity examination among females.[21] For females, screening attendance was better in urban areas. However, for oral cavity examination among males, uptake was better in rural areas, with Tripura and Nagaland reporting the lowest attendance.[21] On a national level, Mizoram ranked third in cervical and breast examinations, while Sikkim was placed second for oral cavity examination.[21]

Given the dearth of studies reporting from the NE region in understanding uptake and barriers to screening behaviors, studies from other parts of the country show that Indian women were reluctant and disappointed to participate in cervical screening as they had no symptoms but had expected treatment for other health-related issues for which they were experiencing symptoms.[23,24] Consequently, it is possible that negative or unmet expectations may result in dissuading women from participating in future screening programs or follow-ups. Likewise, higher rates of loss to follow-up have been found when diagnostic follow-up with colposcopy or biopsies was not given on the same visit.[25,26] Therefore, a "screen and treat" at the same visit proposal was made to minimize delays and loss to follow-up. These findings suggest that it is important to consider individual experiences, knowledge, expectations, and cultural differences in cancer screenings.

Cultural adaptation to awareness campaigns and interventions on tobacco control, alcohol abuse, and risks of certain ethnic food habits should be implemented through media, counseling, and local support.[9,23] Given the significant investments in financial resources, workforce, and substantial work to organize and sustain screening camps and programs to improve health services, a need to involve a variety of stakeholders (e.g., family members, social scientists, public and private healthcare partnerships) becomes imperative for the successful implementation of screening programs and health campaigns.

Role of Family in Cancer Care

Given the high incidence of cancer in the NE region, the family's role is pivotal in supporting its family member diagnosed with cancer. It is observed that the participation of the primary family caregiver(s) in the consultation helps improve communication with the physician(s), adhere to the treatment regimen, and yield improved health outcomes.[27] Further, the involvement of the primary family caregiver(s) in the cancer trajectory acts as a gatekeeper in safeguarding prognosis and treatment-related information based on the response by the patient.[27] Apart from medical-related support, the family plays an important role by providing financial assistance and addressing the psychosocialconcerns of the patient. For instance, Imchen highlighted the emotional support of the family as a contributing factor to resilience in the patient which resulted in adherence to the treatment regimen.[28] Given the collectivist nature of the society, the family and the community serve as a buffer for the patient to fall back to and collectively share the pain and hold space when transitioning from treatment to palliative care.

Navigating Healthcare Services in Nagaland —A Special Reference

Among the NE states, Nagaland is observed to be one of the highest per capita burden of cancer.[6] The cancer of the nasopharynx is reported to be the highest in the country.[9] This is attributed to the presence of a genetic risk possibly hinted toward the southeastern region of China, widespread consumption of tobacco, food habit that includes smoked meat and fish, and poorly ventilated house.[5,9] Despite the high cancer incidence in the state, the public health infrastructure is underdeveloped. This includes a lack of trained workforce and a lack of tertiary healthcare facilities, such as an absence of a medical college (the only state in India), a state cancer institute, and a regional cancer center. Further, there is only one radiotherapy facility in the six cancer-treating hospitals and the absence of a positron emission tomography scan in the entire state.[6]

Consequently, there is a general sense of mistrust in the general public when it comes to availing public healthcare services, with preference given to private healthcare services, especially for tertiary healthcare. Most tertiary healthcare services are availed out of the state, posing practical challenges.[29] While some cases are referrals made by the physician to other hospitals out of the state, most individuals have to navigate the healthcare systems by themselves. Such individuals and their families often have to rely on word of mouth from family, friends, and relatives to choose the physician and the hospital.

Furthermore, Imchen reported that the OOPE by the patients during their treatment surpassed their annual household income.[28] A patient with an annual household income of Rs 70,000 spent Rs 5,00,000 in their treatment expenses.[28] This complex pathway to accessing health services led to delayed diagnosis and expensive treatment processes with poor health outcomes.

Responding to the dire need for appropriate healthcare, on August 2018, the Government of Nagaland signed a Memorandum of Understanding with Tata Trusts to implement a program for providing a comprehensive tertiary cancer care center in the state capital.[30] The main agenda is making cancer care in the public health system more accessible and affordable.

Way Forward to Address the Cancer Burden and Disparity in Cancer Care Delivery

Hub and Spoke Model

Given the pooling of healthcare services in places of commercial and political importance, there is a polarization of accessibility to healthcare with the marginalized and low-income groups being affected the most. Further, the country's scattered geography and multicultural population poses a challenge in implementing quality health systems. Therefore, there is a proposal to adopt a hub and spoke model in healthcare.[31] This model is based on a centralized hub that hosts tertiary healthcare services. On the other hand, the spokes oversee the primary and secondary healthcare services. In this manner, resource allocation is optimized while minimizing cost, a key feature that is important for low- and middle-income countries.

Patient Navigation

To address the growing concern of unequal cancer burden in the country, Tata Memorial Center, a premier cancer center in India, in collaboration with the Tata Institute of Social Sciences, developed a full-time, 1-year Post Graduate Diploma in Patient Navigation (KEVAT).[32] It seeks to implement a similar template in the resource-constraint Indian health system scenario by providing a structured form of access and care for the patients in their cancer trajectory. A first of its kind in the country, KEVAT was launched in the year 2018. The patient navigation program attempts to create a workforce to help the patients diagnosed with cancer and survivors to access care, navigate the complex health systems, consult with the team of physicians, treatment, rehabilitation, insurance, and palliative care.[32] Further, the patient navigators help to create a buffer to the ever-growing load on the healthcare professionals.

Physician Assistants

Similar to the patient navigators, the role of physician assistants merit attention to diffuse some of the responsibilities of the medical care professionals.[33] Physician assistants work closely and physicians supervise it. They are responsible for holding numerous duties in various disciplines in the healthcare system. The physician assistants hold limited license to practice and can examine patients, order diagnostic tests to carry out, interpret test results, provide medical information, and prescribe medications.[33] Given the nature of their role, physician assistants have immense scope to provide cost-effective and pragmatic solutions to our fragile healthcare system.

There is also a need to scale up patient navigation and physician assistant programs nationwide to tackle short-staffed medical care professionals and improve care and delivery of health. Specifically, to create a sustainable, long-term accessibility to cancer care in the state of Nagaland, there is an imperative need to set up a medical college to put the basic health systems in place, without which the operation will not be successful.

Furthermore, the implementation of e-health in disseminating health awareness can be an added advantage. Given the psychological distress involved in cancer diagnosis, it is pertinent that social workers, counselors, and health psychologists provide services in the cancer care continuum. This would enhance the triadic communication (patient, primary caregivers, and physician(s)) for effective adherence to treatment regimen and agency over medical decision-making. Additionally, given the unique multicultural setting of the country, a culturally and socially appropriate approach should be incorporated into the programs to focus on inclusivity and equitable access to cancer care.

Note

The manuscript, “The conundrum of the cancer burden and disparity in cancer care delivery in NE India, with special reference to Nagaland,” has been read and approved by the author (Matsungshila Pongener) that the requirements for authorship have been met, and that the author believes that the manuscript represents honest work.

Authors’ Contributions

Matsungshila Pongener contributed to the concept, intellectual content, literature search, manuscript preparation, manuscript editing, and manuscript review.

Conflict of Interest

None declared.

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Cancer and Spirituality—Underutilized Resource for Cancer Care in India

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Abstract

Living with cancer is a challenge to the individuals and their families. This is a personal perspective of a person living with a diagnosis of cancer for over a decade and as psychiatrist supporting others in a similar situation and their caregivers. The challenges are medical, psychological, social, and spiritual. In the care of persons living with a diagnosis of cancer, there is a need to mobilize all of the resources toward relief and recovery. In the Indian context, to make sense of the uncertainties, spirituality in various forms is harnessed by the patients and their families. Epics and religious stories are routinely used to make sense of the pain, distress, and uncertainties of living with cancer. It is for the caregiving professionals to understand this rich resource in India, and develop ways of maximizing the value of spirituality in the care programs. Systematic study, documentation, and adaptation of the spiritual resources of different religions and communities in the cancer care could be an important Indian contribution to cancer care in the world. Such a development could be similar to the universal acceptance of the value of yoga in the recent years.

Keywords
- spirituality
- uncertainty
- religion
- gratitude
- culture

Introduction

The diagnosis of cancer is a life-changing experience for the affected individual and their families. Recently, a friend called to share the news of being diagnosed with cancer, "my life as I knew is not there now!" It brought back several personal memories of the time I came to know of my diagnosis of colon cancer in 2013. The first thought, I shared with my wife, following the colonoscopy and diagnosis of cancer, was this: "Life as we know is over, but we can build a new life."[1]

This personal perspective is based on the experiences of living with a diagnosis of cancer for over a decade and as psychiatrist supporting others in a similar situation and their caregivers.

It addresses the following aspects of cancer care, namely, (1) impact of cancer diagnosis, (2) the Indian scientific literature on cancer and emotional health, (3) international research in this area, (4) some clinical anecdotes of use of spiritual resources in caregiving as a psychiatrist, and (5) reflections for future work to fully utilize the spiritual resources as an essential and integral part of cancer care.

Impact of Cancer Diagnosis

Current Chief Justice of India, Honorable D. Y. Chandrachud, on December 17, 2023, as part of Sri. E.S. Ventaramaiah Centenary Oration, at Bangalore, Karnataka, India, shared his experience with cancer as follows: "in my own personal life, I was the sole caregiver of a spouse who was battling cancer for almost a decade." Ms. Harmala Gupta, founder of CANSUPPORT in Delhi, has written her experiences ("Cancer, the life changer") in the book, "Life After Cancer" published by the Indian Cancer Society as follows: "There is no getting back to

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the way it was, for you and the members of the family."[2] It is significant that she has utilized the pain of her personal journey, to establish the biggest free home care palliative care program in Delhi. Similar are other experiences: "Suddenly at [age] 35, I get this stage 4 cancer diagnosis, and it's just like a bomb went off and everything around me is debris."[3] "But you are immobilized with uncertainty. It takes a long, long time to push despair away and bring hope back into your life. I will miss a whole bunch of things that I love. But that is what dying is all about. You get one life, you enjoy it as responsibly as you can, and then you die."[4]

Cancer and Emotional Health Studies from India

Epidemiological studies have shown that persons living with a diagnosis of cancer have higher rates of emotional disorders in all countries.[5–7] Indian research in the area of psycho-oncology has addressed the prevalence of emotional health problems,[8–11] need for assessment of needs,[12–14] importance of family,[15] issue of suicide,[16] need for emotional support,[16,17] and the importance of communication in cancer care.[18] A special area of studies have been in spirituality.[19–24] Gielen et al[22] report that more than half of the Indian cancer patients need spiritual care. An Indian measurement has been developed to measure spirituality and its utility has been evaluated.[23,24] Value of yoga has been reported.[25] Another area of recent interest is the scope for posttraumatic growth (PTG) in cancer experiences.[26]

Scientific Evidence of Relationship between Cancer and Spirituality

Koenig[6] reports on 29 studies relating to cancer and spirituality to the relationship between religion/spirituality (R/S) and either the onset or outcome of cancer, including cancer mortality. Of those 16 (55%) found that those who are more R/S had a lower risk of cancer or a better prognosis, although 2 (7%) reported a significantly worse prognosis. Of the 20 methodologically most rigorous studies, 12 (60%) found an association between R/S and lower risk or better outcomes and none reported worse risks or outcomes. The results from some of these studies can be partially explained by better health behaviors (less cigarette smoking, alcohol, abuse, etc.), but not all effects are explained by better health behaviors, it could be explained by lower stress levels and higher social supports in those who are more R/S. Although cancer is not thought to be as sensitive as cardiovascular disorders to show psychosocial stressors, psychosocial influences in cancer incidence and outcome are present.

Emotional Health Support as Part of Cancer Care

There is growing evidence that support of different varieties of psychosocial interventions can alleviate the distress and in some cases improve the survival time. However, there are two challenges in receiving/providing emotional support to persons living with a diagnosis of cancer. First, there is limited mental health professional resources in cancer care facilities in India. Second, there is reluctance of the people to utilize the available mental health specialist services because of stigma and discrimination associated with mental disorders. This is a paradoxical situation, as the diagnosis of cancer is the time you need the greatest support and it is at that time point that you feel most isolated. Faced with the multidimensional challenges, namely, medical, personal, family, financial, social, and spiritual challenges, there is need for support in all of these areas. It is for all of these reasons of the great need and difficulties of providing the needed emotional care, measures to address the need through "self-care" become urgent.

There is an urgent need to not only think of services and supports for emotional health care, but also strengthening the individuals living with a diagnosis of cancer and their caregivers, by harnessing the resources within. In India one of the preexisting sources of support is the spiritual resources. Spirituality, in all religions, addresses the problems faced by a person experiencing pain, suffering, fear of death, and to find meaning of life in adverse life situations. As noted earlier, the diagnosis of cancer is a life-changing situation and is eminently suited for utilizing the preexisting spiritual supports.

Professional Experiences of Providing Emotional Support in a Cancer Hospital

Following my own life journey with cancer,[1] I wanted to utilize my personal/family experiences and mental health professional expertise to assist people living with cancer. I worked as a volunteer psychiatrist at the Sri Shankara Cancer Hospital (SSCH), Bangalore, Karnataka, India for about 2 years. The experiences described below illustrate the importance of spirituality in cancer care in India.

When I started work at the SSCH, in 2015, there was already a professional social worker with decades of cancer care experience, and a senior and experienced psychiatrist providing psychosocial care. When I met them for the first time, both of them said to me, "why are you coming, patients do not come even when they are referred by the oncologists." Further, about spirituality, one of them said: "the topic is of interest to me but I am a little curious/apprehensive to know if people would be open to talk about spirituality...or perceive it to be a private personal affair."

These responses puzzled me, as it was contrary to my personal experiences. However, I went on to work there for nearly 2 years and found their conclusions were not correct. I understood the reason for the reluctance to seek professional help. The two professionals were using the referral and specialist approach rather than working to empower the people/families living with a cancer diagnosis. For the first few months, I worked with all patients receiving chemotherapy. The focus of my interaction was to understand the needs of the people and the ways they were addressing the challenges of diagnosis, treatment procedures, the side effects, cost of care, interpersonal relationships within the families, uncertainties of life, and the resources they were utilizing to address these needs. I used to begin with the two questions: how has your life changed with a diagnosis of cancer? What has helped you in this journey with cancer? Following these I would ask about how I could help them. Unexpectedly, during these open-ended conversations to understand the cancer journey, I understood that persons living with cancer and the caregivers were most often utilizing their spiritual resources, to cope with the multiple challenges. Here are few examples of the use of spirituality as part of cancer journeys.

Pain

One person with severe pain shared what helped her: “I have read somewhere that when Shri Raman Maharshi was enduring the pain of Osteocarcinoma, someone asked him “Swamyji, is it not painful?’ to which he answered, “It’s not ‘me’ but it is ‘the body’ which is undergoing the pain. I am aware of the pain.” These words appealed to her greatly during the chemotherapy days and she would repeatedly tell her mind that “it’s my ‘body’ not ‘me’ who is undergoing the pain.” The spiritual story provided a role model to address a life challenge.

End of Life

An elderly lady with terminal cancer was calm about her life situation and the uncertain future. On enquiry about what helped her, in the challenging life situation, she said: “doctor, I read every day Sunderakanda for about 90 minutes and it gives me peace.” On further enquiry, she said: “In Sunderakanda Matha Sita is in Ashokavana and for all practical purposes there was no hope. However, she maintained hope and a solution came. I believe something similar will happen in my life.” I saw how comparing personal life situation to a spiritual situation helped navigate the uncertainties of future.

Fear of Recurrence

One of the fears of persons living with cancer during the recovery face is the “fear of recurrence.” A 35 years old lady with triple negative breast cancer shared as to how she addresses this challenge. She narrated the story from Mahabharata. She said, “Faith and Fear can’t co-exist.” The story was that of Krishna and Balarama walking through the forest and meeting a demon. The fear of Balaram makes the demon huge while the faith of Krishna reduces the demon to a puppet.

Accepting Death

During the last 1 year I was partner in the end of life journey of a senior psychiatrist and a dear friend,[27] we examined the issues of end of life situation, from both personal and professional viewpoints. It was a rich learning experience for me and taught me that it is possible to face death positively, as my friend did. One interaction stays in my mind forever. In one of the conversation, in response to issue of death, he said, “How hard one may strive, death is a reality. Even Hiranyakasyap and Ravana, who were blessed with immortality, had to die. Death is a blessing. It creates space for new viable life.” Looking at this interaction of many sessions/hours, I can say that my friend found more solace from spirituality than my professional skills.

Overcoming Guilt

About three decades back, I was treating a middle-aged lady with severe depression, associated with the death of her younger brother who had chronic renal condition. She felt guilty about not donating her kidney and save her brother. Literally nothing worked in my therapy. At one point, I shared the story of Buddha and Kissa Goutami and the reality of death. This story was so effective that we could start a new therapeutic journey to recovery. Here, spirituality was more powerful to open new avenues for recovery.

Living in the Present

In a situation of uncertainty, like with a diagnosis of cancer, the past becomes largely irrelevant, the future is uncertain, and the present becomes the only thing to hold on to. However, most of us have not learnt to live in the present, in the truest sense. Learning to live in the present, often referred to as mindful living, has to be learnt, along with putting the past and the future in the back burner.

Religious Texts as Support

A senior academician with multiple recurrences of breast cancer and in an end of life situation, shared how reading Bhagavatham helped her. She said: “Every evening my husband and myself read the book for about an hour. It gives me peace of mind.” When I asked to give an example, she related the story of Parikshith. “Parikshith, facing death within one week, chose to leave his kingdom and move to live in Varanasi with the sages and devote time in spiritual practices.” She whispered to me, “doctor do not feel bad if I tell you, in my current life situation, my spirituality is greater value than medical help!”

Posttraumatic Growth

One of the important developments in the disaster mental health field is the possibility of PTG. This is reported to occur in about one-third of survivors. There is growing literature of PTG in cancer survivors. Some examples will illustrate this aspect. “I feel a sense of purpose I didn’t have when I was 22 and totally adrift. ..there’s also at richness to be excavated; in fact, those transitional moments have ultimately been the most powerful and pivotal of my life.”[28]

“This ordeal taught me to cherish life and its simple joys that we all take for granted. More so, I started looking at my relationships in a new light. I started loving those relationships, my friendships that I had often taken for granted.[29]

“Living with Cancer” Group

During the last few years, I am coordinating a WhatsApp group (myemotionalhealthin.com) of persons living with a diagnosis of cancer and their caregivers. In the group members have been sharing the value of the four “pillars” of cancer care, namely, medical care, psychological support, social support, and spirituality.

Table 1 Approaches to develop practice of spirituality and evaluate its impact (modified from[30])

• Examination of the concepts of pain, suffering, death in different religions
• Adaptation of the concepts/practices to modern societal realities in rural, urban, and other settings and different population groups
• The documentation and dissemination of case studies of persons with a diagnosis of cancer/caregivers utilizing these measures and finding meaning of life
• Preparing people living with cancer, to include spirituality in the overall life plans
• Case–control studies of people with varying degrees of spirituality and cancer outcomes
• Longitudinal studies of persons with a diagnosis of cancer/caregivers to understand the value of spirituality in promoting QOL, mental wellness, preventing distress, depression, and coping better with adverse life situation
• Adaptation and standardization of spiritual practices as applicable to cancer care
• Training of all care categories of providers in spirituality as part their work
• Wider dissemination of lessons learnt in the society—people and patients

Abbreviation: QOL, quality of life.

These professional interactions have taught me that spirituality is a resource people harness when they have medical challenges in general and cancer in particular.

Some Reflections

Cancer changes life. There is need for utilization of all the resources to find relief from "distress" and strengthen persons living with a diagnosis of cancer. The scientific evidence points to the value of spirituality, reviewed in this article. However, as noted by my colleague social worker, there is considerable ambivalence in the caregiving professions about the best way to integrate spirituality in their work.

Spirituality is like sunshine. It is available and useful to one and all. Most of us live utilizing the benefits of sunlight without acknowledging it. Some of us will use it for better skin color. Some of us recognizing the medical value, will expose our bodies daily to sunlight for vitamin D. Few others will think of using sunlight, using solar cells, for generating hot water and electricity for a wide range of uses. Thus, the same sunlight can give light, improve appearance, or improve health or be a major source of energy for many activities. I see spirituality in a similar manner. It depends on what each one of us want to put to use in personal and professional work.

Another analogy I would use, to explain the utilization of the spiritual resources in cancer care. In the seashore, you see four broad groups of persons. Sea is vast, rich in beauty, and powerful. There will be some who would sit on the beach sand and enjoy the scenery. The second group will enter the water and remain in shallow waters and find satisfaction. Third group will take a boat and go deep into the sea and find greater joy. The fourth group dives into the deep water and see the rich life and find greater fulfillment.

The approach to spirituality is also similar—minimal to maximal. Everyone chooses his/her path. As medical professionals, our aim is to maximize the resources for recovery. Spirituality is one of the important resources in cancer care.

Agenda for Action

In India, recognizing that there is both scientific basis and cultural practices to support the value of spirituality, there is a need to develop an agenda for actions by the professionals (►**Table 1**).

Conclusion

Living with a diagnosis of cancer is a multifaceted challenge for the individual, family, and professional care providers. There is need to maximize the positive resources toward recovery, respite, and palliative care. Spirituality is part of humanity. In India, individuals understand and practice R/S at the level of beliefs, practices/rituals, and philosophy of life to guide them through life. There is growing interest in spirituality in cancer care all over the world. It would be to the advantage of individuals, families, and to a greater effectiveness of professional interventions, to make harnessing spiritual resources as part of the total care. Systematizing the spiritual interventions and making it practiceable would be to the advantage of the cancer care programs in the world. Here lies the challenges and opportunities for cancer care practitioners in India.

Conflict of Interest

None declared.

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Editorial Commentary

Coming Full Circle: Concluding Remarks for the Special Issue on Psycho-Oncology in India

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This special issue on psycho-oncology in India is the first ever compilation of scientific articles on this subject matter published in the country. This special issue showcases the wide range of research emerging in India—from detailing the psychosocial needs of people with cancer to the intersection of psycho-oncology and technology. Through review articles, empirical work, and perspective pieces, the reader is introduced to the scope of psycho-oncology research and practice within India.

There are several aspects of this special issue that are noteworthy. First, this issue includes six original articles, two review articles, and two perspective/oncology beyond science pieces. This is an apt mirror of the vast growth that this field has seen in the past two decades in India—there is so much evidence waiting to be published and here we are doing exactly that! Second, the editorial (or foreword) for this special issue is written by Prof. Phyllis Butow. Prof. Butow is a world-renowned psycho-oncology professional who made a big dent in the field through the sheer volume of work she has accomplished in her career. It is encouraging to read her editorial, which not only describes the past and present of the field but also offers the opportunity to imagine the future direction of our collective effort in psycho-oncology. Third, the bulk of *IJMPO*'s readership are oncologists and to be publishing a special issue to this group of astute professionals is a fantastic achievement in advocacy, improving patient outcomes and furthering an interdisciplinary scientific dialog. Indeed, it is a privilege and honor that the former editor, Dr. Padmaj Kulkarni, and current editor, Dr. Seema Gulia, enthusiastically and patiently supported the publication of this unique special issue. Fourth, the contributions to this special issue are from authors at various stages of their career. This is an important observation to make as it speaks to the potential, passion, and fresh perspective this can bring to psycho-oncology research in India.

Personally, this special issue feels like coming home to me. I left India to pursue my Master's and then PhD overseas wherein both my dissertation and doctoral thesis were in psycho-oncology. The studies coming from Indian populations were so sparse at the time that I relied heavily on the broader Asian (mainly Japan and China) research in psychosocial oncology while writing up my work. So, when I returned to India in 2011 after my PhD was awarded, I came with the singular objective to add to psycho-oncology literature emerging from India. I was incredibly fortunate to be almost immediately recruited into IIT Hyderabad as a faculty in the Department of Liberal Arts. Here, I had the freedom to explore, conduct research, and publish on a range of topics in psycho-oncology. Our research group, the Health Associated Co-Operative and Supportive (HACOS) group, engage in several topics such as psychosocial needs of parents of children with cancer, sexual satisfaction in survivors of cancers of the reproductive system, unmet supportive care needs among people with cancer, patient empowerment, physician–caregiver–patient communication, improving the skills of nurses in psychoeducation, MedTech for better patient care delivery, and self-care for oncologists. Rooted in a multistakeholder perspective approach, our group works closely with oncologists, nurses, technicians, scientists, engineers, patients, caregivers, and communities. Given this, publishing the special issue is particularly close to my heart as it feels like our shared journey came full circle.

The structure of this special issue was imagined in a manner so as to provide critical insights into care delivery (e.g., Mukherjee et al describe at what time are psycho-oncology services sought after, suggesting how health care systems can design referral protocols), providing support to underserved groups (e.g., Namjoshi introduces the psychosocial care needs of children diagnosed with cancer and their parents), and the types of interventions that psycho-oncology can offer (e.g., Satish et al detail an RCT of an exercise intervention for a specific concern—cancer-related fatigue—which is experienced by people with cancers of the oral cavity). Following on from this, the special issue tackles how

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the pandemic impacted two major stakeholders in oncology care, that is, patients (here Menon et al use a niche group of people with reproductive cancers) and health care providers (here Siddiqui et al provide an important window into how the pandemic affected health care providers in the thick of the storm). Appreciating that cancer's psychological toll permeates to the family of caregivers and health care providers, we included Asha et al's article on how burnout and psychosocial factors interact among these groups. At this point, we wanted to pause and introduce a few distinctive aspects within psycho-oncology. Therefore, we included a perspective piece on survivorship that explores the unmet needs of people who survived oral cancer (Mitra), a review on the burden and disparity in care services in Nagaland (Pongener), and the need to harness spiritual care in India (Murthy). Finally, we wanted to wrap up this issue by examining the way forward for psycho-oncology research in India through Raqib and George's article on innovations in responding to challenges faced by the field in delivering care.

I hope that this special issue offers you a glimpse into not only the vastness of the scope for work in psycho-oncology but also how far research in this field has come in India. It is humbling and inspiring that as a group, we have consistently and tirelessly ploughed on to contribute to the science and practice of psychosocial oncology in India. This special issue is also a call for more collaborative, multidisciplinary approaches to cancer care delivery. So, I hope that this special issue helps inspire us to work together toward improved, optimal oncology care experiences for patients, caregivers, and health care professionals.

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