



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 research⁹ 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 illness¹³ 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 directly³³ 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 pilot³⁵ 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 workers³⁶ or clinical psychologists³⁵ 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 Pre-adolescents 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

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 coping³⁸ 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 members³⁷ 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 professionals³⁹ 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 worldwide⁴⁵⁻⁴⁷ 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.

Limitations

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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