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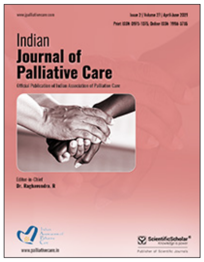
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Original Article

Evaluating the Need for Integrated Pediatric Palliative Care Services in a Pediatric Oncology Setting: A Retrospective Audit

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ABSTRACT

Objectives: Early integrated palliative care has shown to improve the quality of life in patients with cancer. During the past decade, pediatric palliative care has become an established area of medical expertise, however due to scant information available regarding the triggers for referral and referral practice very few children receive a formal palliative care consult.

Materials and Methods: A retrospective audit of medical case records of pediatric oncology patients over a period of 1 year from September 30, 2019, to September 30, 2020, was conducted. Demographic details, diagnosis, staging, clinical parameters, reason for referral, and palliative care plan were captured in a predesigned pro forma.

Results: Among 126 children with cancer, 27 (21.4%) patients were referred to palliative care. Majority 21 (77%) referrals were inpatient consults. Symptom management 17 (44.7%) was the most common trigger for referral followed by referrals for psychosocial support 12 (14.4%). Children with solid tumors 16 (59%) were more often referred than hematological malignancies. Among those needing end of life care, 8 (88.8%) out of 9 families preferred home than hospital.

Conclusion: Low incidence of palliative care referral and presence of symptoms as a trigger for palliative care referral suggests gaps in the integrated approach. The study findings prompt a review of palliative care referral criteria and referral practice in a pediatric oncology setting.

Keywords: Childhood cancer, Early integration, Pediatric oncology, Pediatric palliative care

INTRODUCTION

The WHO defines palliative care in children as the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease.[1]

Cancer is a leading cause of death for children and adolescents worldwide and approximately 300,000 children aged 0–19-year-old are diagnosed with cancer each year.[2] The incidence of childhood cancers in India is rising with age-adjusted cancer incidence rates ranging from 18.6/million to 159.6/million for boys and 11.3–112.4 for girls.[3]

More than 80% of all childhood cancer cases are occurring in low- and middle-income countries, but the cure rates have not matched the figures in the high-income countries, and about 50% of them are dying due to disease or treatment toxicity.[4] In India, cancer is the 9th leading cause of death in the age range of 5–14 years,[5] and hence, it is anticipated that the requirement of palliative care in children with cancer would increase as well.

Specialist pediatric palliative care service is an integral part of many centers treating children with cancer in the high-income countries.[6] However, in India, it is estimated that 1.6 million children with life-limiting and life-threatening illness are in need of specialized pediatric palliative care, but unfortunately, there are very few centers that has the capacity to meet these needs.[7]

At present, there is only one retrospective audit from India that has explored palliative care referral in a pediatric oncology setting (Ghoshal *et al.* 2016). This study was a retrospective audit of medical case records of all children with cancer referred to palliative care. The purpose of this audit was to identify the referral patterns and explore the triggers for palliative care referral and gaps in oncology palliative care integration in a pediatric oncology setting.

MATERIALS AND METHODS

Study patients

Children registered at the division of pediatric hematology and oncology from September 30, 2019, to September 30, 2020, were included in the study. The present study was approved by the Institutional Ethics Committee (IEC Ref: 397/2020).

Data collection and outcome measures

Audit

Data were extracted from the medical case records using a standardized pro forma jointly developed by the pediatric oncology and palliative care team. The data extraction pro forma had details about the patient demographics, clinical information about cancer, and details about palliative care referral. The palliative care referral details included timing and trigger for palliative care referral and palliative care consultation. The audit period was between September 30, 2019 and September 30, 2020.

Statistical analyses

We conducted the statistical analysis using the SPSS software version 20.0 (IBM Corp., SPSS Statistics for Windows and version 20.0. Armonk, NY, USA). Analyses were done with the descriptive summaries of demographic, clinical variables, and patient circumstances at the time of referral and on end–of-life care data.

RESULTS

Patient characteristics

One hundred and thirty-five children with cancer were registered with the pediatric oncology services during the audit period. Nine patients had missing clinical data and were excluded from the audit. Twenty-seven (21.4%) patients were referred to palliative care services, and details of their referral are provided in Table 1.

Among the 27 patients referred, 16 (59.2%) were boys and 15 (55.5%) were 10 years and older. Inpatient consultations constituted majority of the palliative care referral 21 (77.7%).

Caregiver characteristics

Mother was the primary caregiver in 20 (74%) patients followed by father in 5 (18.5%). Only 8 (29.7%) of the primary caregivers had completed their higher secondary schooling (10th standard and above), while 21 (77.7%) had severe socioeconomic constraints and were falling into the lower socioeconomic strata as classified by the Modified Kuppuswamy classification.[8]

Clinical data

As depicted in Table 2, of the 27 patients referred to palliative care services, 16 (59%) patients had a solid tumor of which 14 (87.5%) children had an advanced stage of disease (Stage III or IV). Four (14.8%) patients had a relapsed disease without a salvage therapy or a disease-modifying treatment. Eastern Co-operative Oncology Group score was available in 26 patients with majority patients, 10 (37%) having score of one. About 13 (48.1%) patients received more than one

Table 1: Demographic details.

Items	Categories	*n*=27, *n* (%)
Age (years)	<2	3 (11.1)
	≥2-5	4 (14.9)
	≥5-10	5 (18.5)
	≥10	15 (55.5)
Gender	Male	16 (59.3)
	Female	11 (40.7)
Consult location	Inpatient	21 (77.8)
	Outpatient	6 (22.2)
Primary caregiver	Mother	20 (74.0)
	Father	5 (18.6)
	Grandparents	2 (7.4)
Caregiver education	Illiterate	10 (37.0)
	Up to 5th standard	9 (33.3)
	Up to 10th standard	3 (11.1)
	Graduate	5 (18.5)

Table 2: Clinical data of patients.

Items	Categories	*n*=27, *n* (%)
Type of malignancy	Solid tumor	16 (59.3)
	Hematolymphoid	11 (40.7)
Subtype of malignancy	ALL	8 (29.6)
	Osteosarcoma	04 (14.8)
	Brain tumor	4 (14.8)
	AML	3 (11.2)
	GCT	2 (7.4)
	Ewing's sarcoma	2 (7.4)
	Others	4 (14.8)
Stage	III	6 (18.6)
	IV	10 (37.0)
	Not applicable	11 (44.4)
ECOG	0	5 (18.5)
	1	10 (37.0)
	2	4 (14.8)
	3	7 (25.9)
	Not available	1 (3.8)
Treatment received	IV CT	7 (25.9)
	Oral CT	6 (22.2)
	RT alone	1 (3.8)
	CT and RT	6 (22.2)
	Surgery and CT	4 (14.8)
	Surgery, CT, and RT	3 (11.1)
Number of follow-up OPD visits	0	11 (40.7)
	≤1	5 (18.6)
	>1	11 (40.7)

ALL=Acute lymphoblastic leukemia, AML=Acute myeloid leukemia, GCT=Germ cell tumor, IV=Intravenous, CT=Chemotherapy, RT=Radiotherapy, OPD=Outpatient department, ECOG=Eastern co-operative oncology group

modality of therapy. Fifteen (55.5%) patients were on curative intent therapy, whereas 12 (44.4%) were on palliative intent.

Referral practices

Eleven (28.9%) patients had more than one trigger for referral. The total number of referrals was 38 in these 27 patients. Most common trigger for referral was poorly controlled pain requiring opioid analgesics 17 (44.7%) followed by 12 (31.5%) counseling and psychological support and end of life care 9 (23.6%).

On further review of medical records, we felt that 20 patients who had triggers for palliative care referral were not referred. Of them, 11 patients and their caregivers needed psychological support, 7 had incomplete relief of their symptoms, and 2 children who died at home never had a palliative care consult. We were unable to explore the symptom management and supportive care role of palliative care in patients receiving active cancer directed therapies due to the lack of systematic documentation of symptoms and psychological issues.

End-of-life care practices

Out of the nine patients referred for end of life care, parents of eight patients preferred home as the place of care for the last days of their child's end of life while 1 family preferred to be in the hospital. The preference for home was due to the additional financial burden of hospital stay in 7 out of these 8 patients. General practitioners or family physicians were given a plan of management for these patients.

DISCUSSION

Majority of the referrals to palliative care services worldwide occur very late in the course of disease in children with cancer.[9,10] Such late referrals hamper the delivery of adequate symptom control and guidance required for end of life care.[11] In a retrospective audit done with 1135 case records of children referred to palliative care, it was found that 78.8% of patients who were referred had completed all disease-modifying treatment, and the other 21.2% were on oral metronomic chemotherapy.[12] In our study, 14 (87.5%) children had an advanced stage of disease (Stage III or IV), and only 4 (14.8%) patients had a relapsed disease without a salvage therapy or a disease-modifying treatment. The difference in the pattern observed could be due to the low number of patients in our study.

In the retrospective study done by Ghoshal *et al.*, no children receiving intravenous chemotherapy either with a curative or palliative care intent were referred to palliative care.[12] Although some patients receiving chemotherapy with a curative intent were referred to palliative care, it is a small percentage, and we may not be yet practicing integrated model of palliative care. A prospective, longitudinal, cohort study in children with cancer and noncancer needing hematopoietic stem cell transplantation showed symptom control benefit with early specialist palliative care intervention.[13] However, it was a feasibility study involving small patient numbers, and no specific component of palliative care was assessed. A survey of oncologists, oncology nurses, and patients show that integration of early specialist palliative care in a tertiary cancer center in India improves symptom control, end-of-life care, health-related communication, and continuity of care.[14,15] However, the evidence in pediatric oncology is not robust.

In a study conducted in a large tertiary care hospital, counseling and communication needs were the primary reason for referral to a specialist pediatric palliative care services.[12] The authors attributed the same to limited availability of consultation time per patient in a large volume center. Majority of the patients in our study were referred for symptom control, which was mainly for intractable pain requiring opioid analgesia.

Caregiver's preference for opting end of life care of child could be varied ranging from financial issues to social conditions prevailing at their home.[16,17] Few studies have shown the lack of availability of hospice facility is an important barrier for the delivery of palliative care.[18,19] In our study, except for 1 caregiver, almost all preferred home as their preference during the last days of child's life one of the reasons could be due to nonavailability of hospice attached to the hospital.

This is the second study conducted in a cancer center from India, which has audited the referral practices of pediatric oncology. Our retrospective study had a small number of patients in comparison to previously conducted study in India. It could be a limitation as it may not truly represent the referral practices. Moreover, only a very small number of patients receiving curative intent chemotherapy were referred to palliative care. It might be a limitation as inferences about integration cannot be drawn based on a small number of patients referred. These limitations underpin a need for a prospective study to explore this phenomenon better.

CONCLUSION

Children with cancer in a pediatric oncology setting are infrequently referred to palliative care. The presence of symptoms was a major trigger for referral. More than half of patients referred to palliative care were receiving cancer-directed therapy. However, it was primarily for symptom management. Although a study showed evidence of early integration, due to small numbers, it was not possible to conclude the presence of an integrated model of palliative care. Lack of a hospice attached to the palliative care service prompted the families to choose home as the preferred place of care.

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Declaration of patient consent

Patient's consent not required as there are no patients in this study.

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Nil.

Conflicts of interest

There are no conflicts of interest.

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