Specialist Pediatric Palliative Care Referral Practices in Pediatric Oncology: A Large 5-year Retrospective Audit

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ABSTRACT

Purpose: To audit referral practices of pediatric oncologists referred to specialist pediatric palliative care services.

Patients and Methods: Retrospective review of medical case records of pediatric palliative care patients over a period of 5 years from January 1, 2010 to December 31, 2014. Descriptive summaries of demographic, clinical variables, and patient circumstances at the time of referral and during end-of-life care were examined.

Results: A total of 1135 patients were referred from pediatric oncology with a gradual increasing trend over 5 years. About 84.6% consultations took place in the outpatient setting. In 97.9% of the cases, parents were the primary caregivers. Availability of specialist pediatric health-care services at local places was available in 21.2% cases and 48% families earned <5000 INR (approximately 73 USD) in a month. Around 28.3% of the referrals were from leukemia clinic and maximum references were late with 72.4% patients having advanced disease at presentation. 30.3% of the referrals were made for counseling and communication and 54.2% had high symptom burden during referral. After referral, 21.2% patients continued with oral metronomic chemotherapy and 10.5% were referred back to oncology services for palliative radiotherapy. Only 4.9% patients had more than 2 follow-ups. 90.8% of the patients were cared for at home in the last days of illness by local general practitioners. 70.6% of the deaths were anticipated.

Conclusions: Oncologists referred patients late in the course of disease trajectory. Most of the referrals were made for counseling and communication, but many patients had high symptom burden during referral.

Key words: Oncology, Paediatrics, Specialist palliative care

INTRODUCTION

The 2015 Indian population-based cancer registry reported that the age-adjusted cancer incidence rates of childhood cancers in India are in the range of 18.6/million - 159.6/million in the male pediatric population and 11.3–112.4/million in the female pediatric population. The highest incidence of cancer is observed in the Southern region of India with an incidence of 159.6/million in male pediatric population. The lowest incidence of cancer is observed in the Northeast region of India with an incidence of 18.6 and 11.3/million in male and female pediatric population respectively. Leukemia, lymphomas, and brain tumors are the most common malignancies seen in Indian pediatric population. There is a rising trend of childhood cancers in India,[1] and cancer is the ninth common cause

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of deaths among children aged between 5 and 14 years in India.[2] Pediatric palliative care is an interdisciplinary collaboration, which seeks to improve the quality of life of all children and their families confronted with life-threatening conditions.[3] It focuses on prevention and relief of suffering, regardless of the stage of disease, and comprehensively addresses the physical, psychosocial, and spiritual needs of the child and family.[4-7] The overall goal of pediatric palliative care is to enhance the quality of life for a child with an underlying life-threatening illness.[8-10]

Specialist pediatric palliative care service is an integral component of pediatric oncology services across the world. In North America, specialist pediatric palliative care services are available in 58% of Children's Oncology Group institutions.[11] A survey among pediatricians found that 74% of them expressed reluctance to refer patients to pediatric palliative care services. These pediatricians equated referring to pediatric palliative care services as giving up on patients. They also experienced difficulty with an appropriate timing for pediatric palliative care reference.[12] Elsewhere in the US, a survey conducted among 1200 pediatric oncologists belonging to Children's Oncology Group showed that hospice referral was usually made late in the course of the disease. This was due to pediatric patients receiving prolonged courses of active disease modifying treatment and hospices not accommodating patients on active treatment.[13]

In the United Kingdom, current pediatric palliative care services are provided primarily in the hospital setting. Development of community-based pediatric palliative care programs is integral for coordination, continuity, and provision of quality care.[14] Equitable access to palliative care services is one of the aims set out in the "Improving Outcomes Guidance" published in 2005.[15] In the UK, services vary on a regional basis, but there are common principles used to guide and support referrals. Children are referred to palliative care services via a number of routes; from community-based primary care centers to regional tertiary centers. Identifying those most likely to benefit from the finite resources available can be a challenge, and the health-care professional's negative attitudes to palliative care, has been further identified as a potentially modifiable barrier.[16] Approximately, a third of children and young people, who die from cancer, are referred to specialist pediatric palliative care services; and this proportion has not changed since 1990.[17] Referral to specialist pediatric palliative care services for children with life-limiting conditions has resulted in more children dying in the community (home or hospice) than hospital.[18] These findings are augmented by the fact that for children with cancer in the UK,[19] home is the preferred place of death.

From mid-1980s onward, seminal hospital-based specialist pediatric palliative care services were developed in prominent children's hospital in Oceania such as the Children's hospital at Westmead in Australia and Starship children's hospital in New Zealand.[20] In Malawi, children's palliative care is now part of national policy and the government has committed in rolling out training in these regions. In the Indian state of Maharashtra, children's palliative care is now included in state policy, and there is a dedicated budget set aside for care provision. In the Middle East, specialist pediatric palliative care services were rolled out in the year 2013 in Kuwait. There are some recent promising developments seen in certain Eastern European nations such as Belarus, Latvia and Poland in pediatric palliative care.[21]

Demographics of illness and illness trajectories are different in children when compared to the adult population. Illness trajectories often guide referral practices in palliative care. Physicians and parents are often faced with difficult decisions around benefit and burden of medical treatment and its impact on Quality of Life. The American Academy of Pediatrics recommends the development and broad availability of pediatric palliative care services based on child-specific guidelines and standards.[22] These guidelines should inform clinicians on appropriate palliative care referral practices.

At the Tata Memorial Hospital (Mumbai), specialist pediatric palliative care service is working alongside pediatric oncology since the year 2002. Similar initiates have been seen in very few centers in India such as Hyderabad, Delhi and Trivandrum. In most parts of India, specialist pediatric palliative care is in its nascent stage. According to Global Atlas of Palliative Care, India has attained level two integration, i.e., sporadic distributions of services for provision of pediatric palliative care.[23]

Currently, there is no data on the pattern or numbers of specialist pediatric palliative care referrals in India. Furthermore, there is limited data on optimal referral models that can facilitate early introduction of specialist palliative care. This study was a retrospective audit of pediatric palliative care case records from 2010 to 2015. This study primarily focused on the pediatric palliative care referral practices in a pediatric oncology setting and used the existing data sources to determine usage of specialist pediatric palliative care services in a tertiary cancer hospital in India.

PATIENTS AND METHODS

Study patients

Children presenting to the outpatient clinic and inpatient referrals of the specialist pediatric palliative care service of the Department of Palliative Medicine at the Tata Memorial Centre (Mumbai) over a period of 5 years from January 1, 2010, to December 31, 2014. The Institutional Review Board permitted a waiver of consent and all patients ≤18 years of age receiving specialist pediatric palliative care services were enrolled in the study.

Data collection and outcome measures

Audit

We reviewed participants' inpatient and outpatient clinic notes along with the electronic medical records to obtain data on (1) demographics (domicile status, age, gender, residence and presence of siblings); (2) clinical information (diagnosis, stage, comorbid conditions, triggers initiating referral to palliative care service, symptoms and current treatment); (3) palliative care consultations (assessment, location of patient during consult, persons accompanying at consult, goals of consult, and details of referrals back to oncology services); (4) liaison detail with local general practitioners and their availability and involvement at different time points; and (5) follow-up information (number of phone calls, medical events, death, etc.).

Audit outcome measures included demographic and clinical characteristics of children, reasons for referral, outcomes of referral, liaison details, preferred place of care and end of life care.

Statistical analyses

We conducted statistical analyses using SPSS version 22.0 (IBM Corp., SPSS Statistics for Windows, Version 22.0. Armonk, NY, USA). Analyses were done with descriptive summaries of demographic, clinical variables and patient circumstances at the time of referral and on end–of-life care data. Missing data were noted and excluded from analyses and *P* values of 0.05 or less were deemed statistically significant.

RESULTS

Patient characteristics

A total of 1135 children with advanced cancer presented to the pediatric palliative care clinic from January 1, 2010 to December 31, 2014. There was a steady rise in the referrals to specialist pediatric palliative care over the years during the audit period [Figure 1].

Among the total number of patients referred 818 (72.1%) were male. 602 (53.1%) patients were above 10 years. Around 961 (84.6%) consultations took place in the outpatient setting. In 1111 (97.9%) cases, parents were the primary caregivers. Nearly 914 (80.5%) children had siblings, and they had extended families in 781 (68.8%) of the cases. About 545 (48%) caregivers had completed high school education. Around 545 (48%) of the families had serious economic constraints and earned <5000 INR (approximately 73 USD) per month. Two hundred and forty (21.2%) patients had access to specialist pediatric health-care services at their local place. About 1055 (93%) patients were from places outside Mumbai. Thus only 56 (4.9%) could complete more than 2 follow-ups [Table 1].

Clinical data

Three hundred and twenty-two (28.3%) referrals were from pediatric hematology-oncology unit. Eight hundred and twenty-two (72.4%) of children had a recurrence or progressive disease and not amenable for further disease modifying treatment at the time of referral. Three hundred and thirty-one (29.1%) received chemotherapy as a major treatment modality. Three hundred and seventy-two (32.8%) patients had skeletal metastasis [Table 2].

Eastern Cooperative Oncology Group and Edmonton Symptom Assessment System scores at referral

Four hundred forty-seven (39%) patients had a performance score of 2 on Eastern Cooperative Oncology Group (ECOG) scale [Table 3]. Symptoms were screened using Edmonton Symptom Assessment System (ESAS) scale during the first visit. Caregivers were asked to help for children who were unable to complete. Wong-Baker FACES® Pain Rating Scale was used for children under 8. Severe

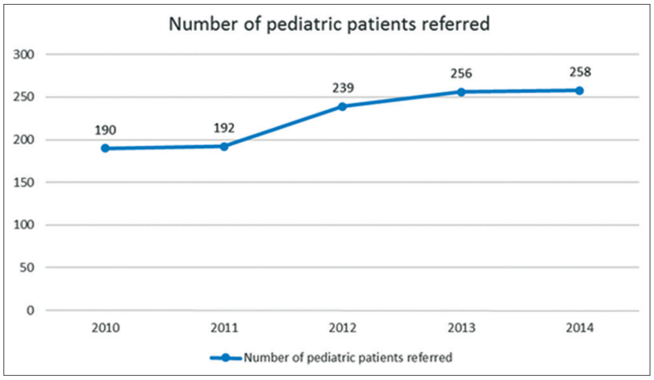

Figure 1: Number of referrals to pediatric palliative care from 2010 to 2014

Table 1: Demography

Items	Categories	*n*	Percentage
Age (years)	<2	90	7.9
	3-5	181	15.9
	6-10	262	23.1
	11-18	602	53.1
Gender	Male	818	72.1
	Female	317	27.9
Consult location	OPD	961	84.6
	IPD	174	15.4
Domicile	Maharashtra (outside Mumbai)	240	21.2
	Mumbai (home care area)	80	7
	Rest of the country and neighboring countries	815	71.8
Primary caregiver	Parents	1111	97.9
	Other relatives	13	1.1
	Grandparents	11	1
Siblings	Yes	914	80.5
	No	221	19.5
Family type	Nuclear	354	31.2
	Joint	781	68.8
Medical facility at local place	General hospital	735	64.8
	Pediatric hospital	240	21.2
	Private clinics	138	12.1
	No data	22	1.9
Caregiver education	Illiterate	34	3
	Up to class X	545	48
	Up to class XII	168	14.8
	Up to graduation	388	34.2
Child education	Pre school	227	20
	Up to class V	351	30.9
	Up to class X	557	49.1
Income (INR)	<5000	545	48
	5001-10,000	272	23.9
	10,001-20,000	113	9.9
	20,001-40,000	125	11.1
	>40,000	80	7.1

OPD: Outpatient department; IPD: Inpatient department

Table 2: Clinical data at baseline

Items	Categories	*n*	Percentage
Number of OPD follow ups	0	851	75
	1	148	13
	2	80	7.1
	≥2	56	4.9
Malignancy	Retinoblastoma	26	2.3
	Medulloblastoma	20	1.8
	Germinoma	10	0.9
	Soft tissue sarcoma	68	6
	Adrenocortical carcinoma	24	2.1
	Lymphoma	34	3
	Glioma	57	5
	Pancreatoblastoma	13	1.1
	Hepatoblastoma	12	1.1
	Colon	16	1.4
	Ependymoma	9	0.8
	Neuroblastoma	70	6
	Ovary	12	1.1
	PNET	206	18.3
	Rhabdomyosarcoma	91	8
	Wilms tumor	15	1.3
	Osteogenic sarcoma	159	14
	ALL	240	21.1
	AML	48	4.2
	Nasopharyngeal carcinoma	5	0.5
Stage	III	25	2.2
	IV	822	72.4
	Not applicable	288	25.4
Metastasis	Bone	372	32.8
	Lung	297	26.2
	Brain	190	16.7
	Bone marrow	125	11
	Liver	70	6.2
	Spinal cord	58	5.1
	Others	23	2
Treatment received in the immediate past	Surgery	26	2.3
	CT	331	29.1
	Radiotherapy	37	3.3
	Chemo-RT	280	24.7
	Surgery and CT	121	10.7
	Surgery and RT	40	3.5
	Surgery and chemo-radiation	300	26.4

CT: Chemotherapy; RT: Radiotherapy; OPD: Outpatient department; PNET: Primitive neuroectodermal tumor; AML: Acute myeloid leukemia; ALL: Acute lymphoblastic leukemia

pain (median score 3) was present in 229 (20.2%) patients, followed by severe loss of well-being (median score 3) in 112 (9.8%), and severe fatigue (median score 2) in 86 (7.6%). Symptoms such as drowsiness, breathlessness and nausea were less common. Since ESAS scoring system was used, depression and anxiety scores were not assessed in children <5 years of age. Four hundred and ninety-one (43.3%) had mild depression (median score 2) and 629 (55.4%) had mild anxiety (median score 3) on ESAS [Table 4a].

Referral practices

Three hundred and forty-four (30.3%) referrals made to palliative care team were for counseling and communication purposes, whereas 243 (21.4%) referrals were for symptom management. Two hundred and eleven (18.6%) referrals were solely for support in decision-making for treatment and in 203 (17.9%) cases no specific goals were mentioned during referral. In the specialist pediatric palliative care clinic, 614 (54.2%) cases received consultation for symptom management and counseling. During these consults, it was seen that 168 (14.8%) had poorly controlled complex symptoms. Discussions regarding cessation of disease modifying treatment were needed in 290 (25.5%) cases and prognostic discussions took place in 63 (5.5%) cases. Two hundred and forty-one (21.2%) patients continued with oral chemotherapy, along with ongoing interventions of pediatric palliative care.

One hundred and nineteen (10.5%) children were needed to be referred back to oncology services for palliative radiotherapy for pain and other symptoms. One hundred and ninety-eight (17.4%) patients needed input for rehabilitation with occupational and physiotherapy [Table 5].

Specialist pediatric palliative care inputs provided as a multidisciplinary approach improved symptom scores during follow-up [Table 4b and c].

End-of-life care practices

About 1031 (90.8%) patients were cared for at home during their last days of life. Around 627 (55.2%) patients died at home (no data in 161 [14.2%] cases). Pediatric palliative care teams provided telephonic support to 752 (66.3%) children and their families. It was difficult to extract the data for the number of calls made, but a trend toward increased numbers of calls being made was found over the years. Death was anticipated in 802 (70.6%) cases (no data in 161 [14.2%] cases). Local general practitioners cared for 722 (63.6%) children (no data in 36 [3.2%] cases) and they provided care following a palliative approach in 722 (61.5%) cases (no data in 58 [5.1%] cases). Most of these interventions were centered on symptom management, but detailed data regarding the nature of intervention were not available [Table 6].

DISCUSSION

Specialist pediatric palliative care service was started in our institute in 2002. However, we could gather data of only last 5 years (2010–2014) as previous records were not available from the archives. Referral patterns tallied with the data from hospital registration with acute leukemia being the most common condition referred from pediatric hematology-oncology. This was more prevalent than other diagnoses due to higher incidence in children and due to the tendency to treat till late in the disease trajectory particular with more patients being offered the option for bone marrow transplant.[1] This is the first study in India to evaluate pediatric palliative care referral practices.

Table 3: Eastern Cooperative Oncology Group scores at referral

Items	Categories	*n*	Percentage
ECOG	I	331	29
	II	447	39
	III	279	25.5
	IV	78	6.5

ECOG: Eastern Cooperative Oncology Group

Table 4a: Edmonton Symptom Assessment System scores at referral

Items (median score)	Number of patients (%)			
	ESAS score 0	ESAS score (1-3)	ESAS score (4-6)	ESAS score (>7)
Pain (3)	252 (22.2)	419 (36.9)	235 (20.7)	229 (20.2)
Breathlessness (0)	891 (78.5)	127 (11.2)	72 (6.4)	45 (3.9)
Fatigue (2)	165 (14.5)	607 (53.5)	277 (24.4)	86 (7.6)
Loss of appetite (2)	187 (16.5)	631 (55.6)	287 (25.3)	30 (2.6)
Loss of well-being (3)	69 (6.1)	549 (48.4)	405 (35.7)	112 (9.8)
Depression* (2)	109 (9.6)	491 (43.3)	177 (15.6)	27 (2.4)
Anxiety^ (3)	72 (6.3)	629 (55.4)	104 (9.2)	29 (2.6)
Nausea (0)	879 (77.4)	176 (15.5)	53 (4.7)	27 (2.4)
Loss of sleep (2)	333 (29.3)	631 (55.6)	152 (13.4)	19 (1.7)
Drowsiness (0)	1025 (90.3)	59 (5.2)	51 (4.5)	0 (0)

*No data in 331 (29.1%) patients; ^No data in 301 (26.5%) patients. ESAS: Edmonton Symptom Assessment System

Table 4b: Change in Edmonton Symptom Assessment System scores

Symptoms	Mean scores (median)	
	Initial	Follow-up
Pain	3.4 (3)	3.3 (2)
Fatigue	2.8 (2)	3.1 (2)
Nausea	0.5 (0)	0.7 (0)
Depression	2.0 (2)	2.0 (2)
Anxiety	2.6 (3)	2.3 (2)
Drowsiness	0.2 (0)	0.1 (0)
Loss of appetite	2.6 (2)	2.8 (3)
Loss of well-being	3.3 (3)	3.8 (3)
Loss of sleep	1.8 (2)	1.9 (2)
Dyspnea	0.5 (0)	0.3 (0)

Our pediatric palliative care team participates in tumor board discussions alongside pediatric oncology disease management group to facilitate a smooth transition of care. However, most of the patients are referred in an advanced stage of disease after multiple lines of therapy. Studies show that worldwide pediatric oncology referral takes place late in the course of illness trajectory,[24-26] which precludes early specialist palliative care referral.[27] A qualitative study has shown that late referral to pediatric palliative care may be also due to patients' and their families' reluctance to access palliative care services.

Table 4c: Test statistics of Wilcoxon signed ranks test

	Change in pain scores	Change in fatigue scores	Change in nausea scores	Change in depression scores	Change in anxiety scores	Change in drowsiness scores	Change in appetite scores	Change in loss of well-being scores	Change in loss of sleep scores	Change in dyspnea scores
Z	−0.025[b]	−1.533[c]	−1.651[c]	−1.352[c]	−1.365[c]	−1.000[b]	−2.398[c]	−2.886[c]	−2.016[c]	−0.183[c]
Asymptotic significant (two-tailed)	0.980	0.125	0.099	0.176	0.172	0.317	**0.016**	**0.004**	**0.044**	0.855

[b] Based on positive ranks; [c] Based on negative ranks

Table 5: Referral practices

Items	Categories	*n*	Percentage
Recommended interventions by palliative care team	None	558	49.2
	Radiotherapy	119	10.5
	OMCT	241	21.2
	OT/PT	198	17.4
	No data	19	1.7
Goals of pediatric palliative care consult as identified by pediatric oncologists	Symptom management	243	21.4
	Counseling	344	30.3
	Decision-making support	211	18.6
	Coordination of care	32	2.8
	Discharge planning	89	7.9
	DNR discussions	13	1.1
	No specific goals mentioned during referral	203	17.9
Palliative care needs identified by the PPC team during initial referral	Poorly controlled symptoms	168	14.8
	Discussions regarding cessation of disease modifying treatment	290	25.5
	Clarifying prognosis	63	5.5
	Routine palliative care consult	614	54.2

OMCT: Oral metronomic chemotherapy; OT/PT: Occupational therapy/physiotherapy; PPC: Pediatric palliative care; DNR: Do not resuscitate

Table 6: End of life care practices

Items	Categories	*n*	Percentage
Death nature	Anticipated	802	70.6
	Not anticipated	172	15.2
	No data	161	14.2
Death location	Home	627	55.2
	Hospital	336	29.6
	No data	161	14.2
	Hospice	11	1
Place of care	Home	1031	90.8
	Hospital	81	7.1
	Hospice	23	2.1
Phone follow-ups	Done	752	66.3
	Not done	383	33.7
LGP consultations after going back to community	Done	722	63.6
	Not done	377	33.2
	No data	36	3.2
LGP interventions for palliative care	Symptom management	698	61.5
	Re-referral to higher centers	379	33.4
	No data	58	5.1

LGP: Local general practitioner

Our results demonstrate that oncologists prioritized counseling and communication needs as the primary reason for referral when considering referral to specialist pediatric palliative care services. This may be due to high burden of psychological distress in patients and families as perceived by the oncologist.[28,29] These perceptions correlate with anxiety and depression scores measured using ESAS during initial assessment. As the oncologists were familiar with the structure of pediatric palliative care multidisciplinary team, they were confident in referring patients and their families for counseling, completing communication, and assistance with treatment decision-making. These findings correlate with studies that have demonstrated that palliative care teams handle communication issues effectively.[30] Less percentage of referrals for symptom management may be due to oncologists not being able to recognize these symptoms as distressing.[31] This could be also due to limited availability of consultation time per patient with a large number of patients in a resource-limited set-up.

Studies from other countries have shown that lack of availability of hospice and specialist pediatric palliative care service is an important barrier for pediatric palliative care referral.[32-35] Lack of awareness about scope of specialist pediatric palliative care among oncologists may be an important barrier for very low percentage of palliative care referral in our study. Awareness about scope of comprehensive specialist pediatric palliative care services may source more referrals.

Majority of children were referred to the outpatient clinic. Studies show that outpatient provision of palliative care enables earlier and more collaborative involvement of specialist pediatric palliative care.[36,37] Insurance policies in the United States are the most influential factor determining timing of the referral for the oncologists. It prevents the specialist pediatric palliative care team from accepting patients on active disease-directed chemotherapy.[38] There are no Indian insurance considerations preventing involvement of palliative care services during active chemotherapy. Although inclusion of specialist pediatric palliative care clinician in tumor boards should have ideally encouraged earlier referrals, according to this audit, the percentage of referral still remains low.[39,40]

In an Australian study, experienced physicians were more likely to refer to specialist pediatric palliative care services. Controlling for age and specialty, those who completed a rotation in palliative care during their residency would be likely to refer to palliative care early.[36,41] Hence, encouraging the trainee pediatric oncologists to have palliative care rotation may facilitate understanding of the scope of pediatric palliative care services and improve referral.

Studies have shown that oncologists feel that referral to specialist pediatric palliative care represented an abandonment of their patients or added too many providers. Hence, they were uncomfortable referring patients to a service called palliative care unless and until they were close to death. Despite the small numbers, this factor may be a predictor of referral frequency. It is not clear if pediatric oncologists were comfortable in discussing end-of-life issues and providing palliative care themselves.[42] In a study at a US cancer center, one-third of physicians indicated they would likely refer earlier, if palliative care was renamed supportive care[43] and an actual change of service name was associated with earlier outpatient referrals.[44] Our study was unable to capture this data.

This is the first study that has examined a large data from a tertiary cancer care institute from India that examined pediatric palliative care referral practices and identified palliative care needs of children with advanced life-limiting illness. The data were sourced from both manual and electronic medical records to minimize errors and avoid missing data. Limitations can be ascribed to its retrospective nature.

Future studies need to focus on formulating a set of criteria, which can facilitate the creation of a robust referral system. It will provide early palliative care to those children and families who need them the most.

CONCLUSIONS

- Although referral to specialist pediatric palliative care has increased over the years, the percentage of referral still remains small
- Most of the patients were referred for counseling, communication, and symptom management
- Majority of patients referred to specialist palliative care had advanced acute leukemia
- One-third of patients receiving pediatric palliative care received concurrent oral chemotherapy.

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Conflicts of interest

There are no conflicts of interest.

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