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Original Research Article

Assessment of palliative care in chronic hematological conditions in children in a tertiary care hospital

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ABSTRACT

Background: The aim of palliative care is most certainly the improvement of quality of life of patients suffering from various haematological diseases like leukaemia, haemophilia, thalassemia owing to the importance of palliative care in ensuring quality end-of-life care, provision of palliative care has been identified as an international human right. The objective of this study was to asses palliative care in chronic haematological conditions using Paediatrics palliative screening scale (PaPaS).

Methods: 71 cases who fulfilled inclusion and exclusion criteria were included in the study for assessment of palliative care. Then, the data was analysed using the Statistical Package for Social Sciences (SPSS) software (version 13) and descriptive and interferential statistics were used.

Results: In leukaemia patients the mean PaPaS score was reported to be 23.58 (SD: 7.43). Nineteen participants (61.29%) had a PaPaS score of >25 and 12 participants (38.71%) had PaPaS score of less than 25. In thalassemia patients the mean PaPaS score was reported to be 27.42 (SD: 6.54). Twenty participants (64.52%) had a PaPaS score of >25 and 11 participants or 35.48% had PaPaS score less than 25. In haemophilia patients the mean PaPaS score was reported to be 32.88 (SD: 4.94). Seven participants (87.5%) had a PaPaS score of >25 and only single participants or 12.5% had PaPaS score less than 25. In lymphoma patient the PaPaS score was 34.

Conclusions: Chronic hematological diseases have lot of unmet needs of palliative care and study calls for creation of hospice and palliative care facility in all hospitals to meet the unmet needs of palliative care.

Keywords: Palliative care, Hematological conditions, Children, PaPaS scale

INTRODUCTION

Paediatric palliative care is specialized medical care that seeks to improve the quality of life of all children with serious conditions, as well as their families.[1]

Palliative care focuses on providing relief from the symptoms and stress of the illness, regardless of the stage of disease, and comprehensively addresses the physical, psychosocial, or spiritual needs of the child and family.[2-4]

Palliative care is based on need, not prognosis, so it is best to bring the team in early.

Palliative care increasingly is recommended throughout treatment for number of illnesses, including those for which cure remains possible or even likely.[5,6]

A number of assessment tools are designed to assess the need for palliative care at early stages of various medical disorders e.g., Edmonton symptom assessment scale (ESAS), Paediatric palliative screening scale (PaPaS).

Because of inadequate data to advocate its use for assessment of palliative care, the current study was designed for assessment of palliative care need in children with chronic haematological disorders.

METHODS

Study design, settings, and participants

The study was a cross-sectional observational study.

The study was carried out in the department of paediatrics of Indira Gandhi Government Medical College, Shimla, that caters to the urban and the rural populations of the hilly district.

The assessment of paediatric care needs of the patients was done in out-patient and in-patient setting.

The study was conducted during the period of one year (September 2020 to October 2021).

71 cases who fulfilled inclusion and exclusion criteria were included in the study. Study was approved by the institute ethic board.

Inclusion criteria

Candidates belonging to ages of one month to 18 years were included in the study. candidates suffering from the following conditions were enrolled-

Haematological conditions

The diseases or conditions that pertain to blood and blood forming organs are grouped under the category of haematological disorders.

The haematological disorders included the study were based on the following criteria: (a) life threatening conditions for which treatment is available but might fail; (b) conditions where premature death is inevitable; and (c) progressive conditions without cure.

Diseases included

The following diseases were included in the study: (a) thalassemia; (b) haemophilia; and (c) haematological cancers.

Exclusion criteria

The neonates and non-consenting or non-assenting parties were excluded.

Modified paediatric palliative screening scale (Modified PaPaS scale) which is a performa based oral questionnaire was used to assess the need of palliative care in the study groups. For Modified PaPaS scale refer to Annexure 1. Modified PaPaS scale which is a performa based oral questionnaire is based on the following domains:

Domain 1

Expected life expectancy.

Domain 2

Expected outcome of current treatment and burden of this treatment.

Domain 3

Performance status.

Domain 4

Symptom and problem burden.

Domain 5

Preferences of patient, family and health professional.

Statistical analysis

The data was analysed using the Statistical Package for Social Sciences (SPSS) software (version 13) and descriptive and interferential statistics were used.

When the total score was less 25, these children were considered having no palliative care needs.

For children with score equal to or greater than 25, need palliative care and the care to be started immediately.

RESULTS

71 cases with chronic haematological conditions (leukaemia, thalassemia, haemophilia, lymphoma) were enrolled in the study and they were assessed for the need of palliative care using modified PaPaS scale. The participants were divided into age groups of class intervals of 5, and the four age groups were constituted and groups are as follows in the Table 1.

Table 1: Showing age group and frequency.

Age groups (years)	Frequency N (%)
1-5	26 (36.62)
5-10	7 (9.86)
10-15	12 (16.90)
15-18	26 (36.62)

In our study, out of 71 cases, majority of the cases enrolled were of thalassemia and leukaemia, being 31 in number. Figure 1 showing diagnosis stratified distribution among various age groups.

PaPaS score in various disease

Variation in the PaPaS score as clinical diagnosis in various domains is depicted in Table 2. In leukaemia patients the mean PaPaS score was reported to be 23.58 (SD: 7.43). Nineteen participants (61.29%) had a PaPaS score of >25 and 12 participants (38.71%) had PaPaS score of less than 25. In thalassemia patients the mean PaPaS score was reported to be 27.42 (SD: 6.54). Twenty participants (64.52%) had a PaPaS score of >25 and 11 participants or 35.48% had PaPaS score less than 25. In haemophilia patients the mean PaPaS score was reported to be 32.88 (SD: 4.94). Seven participants (87.5%) had a PaPaS score of >25 and only single participants or 12.5% had PaPaS score less than 25. In lymphoma patient the PaPaS score was 34.

Table 2: Showing PaPaS score in various clinical conditions.

Domain	Haemophilia N (%)	Leukaemia N (%)	Lymphoma N (%)	Thalassemia N (%)
Domain 1 total				
0-2	0.00 (0.00)	8.00 (25.81)	0.00 (0.00)	7.00 (22.58)
3-4	2.00 (25.00)	8.00 (25.81)	0.00 (0.00)	6.00 (19.35)
5-6	6.00 (75.00)	15.00 (48.39)	1.00 (100.00)	18.00 (58.06)
Domain 2 total				
0-4	4.00 (50.00)	22.00 (70.97)	0.00 (0.00)	19.00 (61.29)
5-6	4.00 (50.00)	9.00 (29.03)	1.00 (100.00)	12.00 (38.71)
Domain 3 total				
0-4	4.00 (50.00)	28.00 (90.32)	1.00 (100.00)	24.00 (77.42)
5-6	4.00 (50.00)	3.00 (9.68)	0.00 (0.00)	7.00 (22.58)
Domain 4 total				
0-5	0.00 (0.00)	3.00 (9.68)	0.00 (0.00)	1.00 (3.23)
5-10	3.00 (37.50)	23.00 (74.19)	1.00 (100.00)	25.00 (80.65)
10-15	5.00 (62.50)	5.00 (16.13)	0.00 (0.00)	5.00 (16.13)
Domain 5 total				
0-5	1.00 (12.50)	13.00 (41.94)	0.00 (0.00)	9.00 (29.03)
5-10	3.00 (37.50)	14.00 (45.16)	1.00 (100.00)	18.00 (58.06)
10-15	4.00 (50.00)	4.00 (12.90)	0.00 (0.00)	4.00 (12.90)

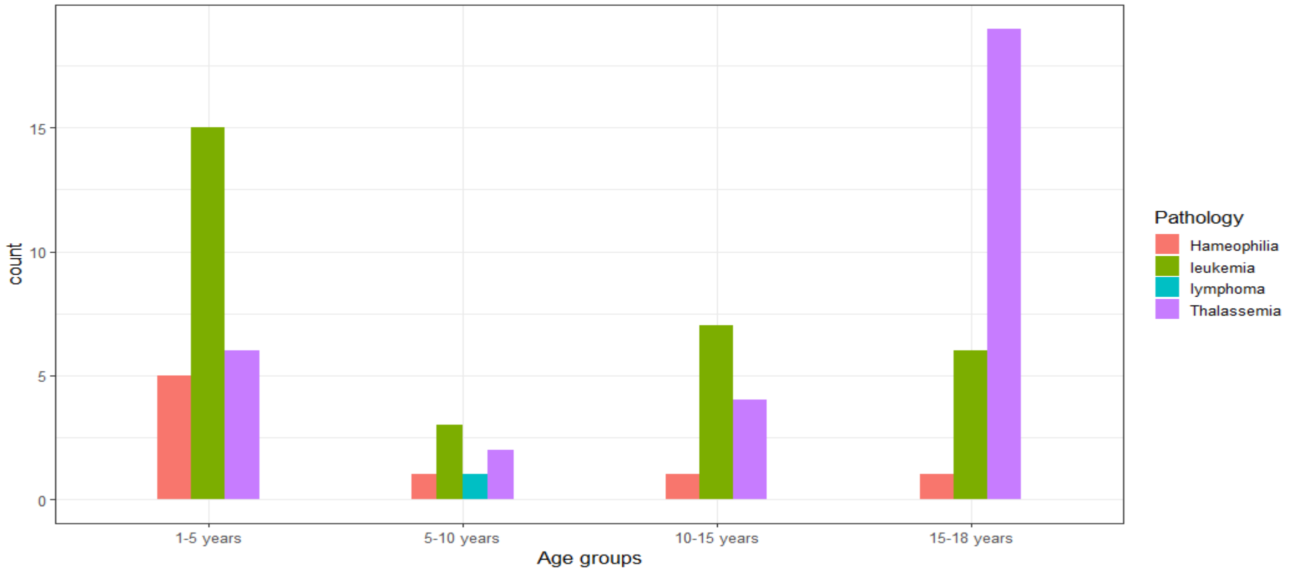

Figure 1: Bar chart of age groups.

DISCUSSION

This study is first of its kind in northern part of India aiming to enhance quality of life for patients with chronic haematological disease. In our study 36% of the participants belongs to 1-5 years, 7% were of age group 5-10 years,16.90% were in age group 10-15 years, 36% were in age group 15-18 years. In the study by Moya et al 33% patients were in the age group of 1-7 years, 24% patients were in the age group of 8-12 years and 12% were in the age group of 13-17 years.[7] They also included new-borns and infants, which were excluded in our study and their study was a large-scale study, moreover the age group taken was different than our study explaining the difference in the results.

In our study, cancer patients (leukaemia and lymphoma) were 45% and non-cancer patients (thalassemia major and haemophilia) were 55%. In a study by Monteros so et al, regarding prevalence of haematological malignancy, categorised children into two groups. He divided children into cancer (14.7%) and non cancer group (85.3%) in his study.[8] In our study children with cancer were 24% and non-cancer children were 76%, which is contrasting to our observation. We assessed the need of paediatric palliative care in chronic haematological diseases using paediatric palliative care screening scale. The objective of the PaPaS scale (Annexure 1) is to improve awareness of paediatric palliative care and its potential benefit for severely ill children and their families. The endpoint of the PaPaS scale is the outcome of a complex process of decision- making.

Formulated in the year 2013 its further validity was checked in a study by Bergstraesser et al and Paul et al in the year 2014 Most studies in the past which were conducted on a large scale took mortality in disease to assess the need of paediatric palliative care in children, this screening scale however takes morbidity into account for assessment of need.[9] In our study in 31 children with haematological malignancy, 7 children had score of less than 15 (92%) (need no palliative care) and 25 had score greater than 25 (palliative care to be started immediately).

Valizadeh et al in this descriptive analytical study, 108 adolescents with haemophilia were selected through convenience sampling. The study showed that Iranian adolescents with haemophilia did not exhibit favourable practice in some fields of prevention of disease complications. Thus, such patients should be provided with adequate information and palliative care to prevent life long and fatal complications of the disease.[10] Downing et al assessed the status of addressal of PPC needs in LMICs and opined that even though innovative approaches and leadership has made way in PPC in LMICs, there is a dire need for action at various levels, viz, clinical, academic and national.[11]

Freudtner et al did a similar study assessing need for palliative care in age 1 year to 20 years in develop nations suffering from various neurological, Musculo-skeletal, leukemic, polysymptomatology were discussed, reported mean age of 4.1 years with 501 participants and 53.3% males' gender-wise and these results were in variance from our study. The older age might be attributed to the later presentation of cases of lymphoma and leukaemia in the LMICs as compared to HICs.[12]

Limitations

The sample size was limited to 71 participants, our observation in variants with the current participants cannot be generalized due to small number of the enrolled cases due to COVID pandemic, therefore large multicentred study should be carried out to assess the palliative care need.

CONCLUSION

This study is first of its kind in northern part of India aiming to enhance quality of life for children. We enrolled 71 children 43 males and 28 females. We found all patients with-leukaemia, thalassemia, lymphoma, haemophilia will require palliative care and this should be started immediately as early as possible. Our study calls for creation of hospice and palliative care facility in all hospitals to meet the unmet needs of palliative care. All patients with chronic and life limiting disease should be assessed on diagnosis for the need of palliative care.

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Conflict of interest: None declared
Ethical approval: The study was approved by the Institutional Ethics Committee

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ANNEXURE 1

Performa

Name

Age

Sex

Birth order

Postal address

Phone no.

Clinical diagnosis

Domain and item number	Item	Characteristics	Score (preliminary)
Domain 1	Estimated life expectancy		
1.1	Estimated life expectancy	>2 years	0
		>1 but <2 years	1
		3 months to 1 year	2
		<3 months	3
1.2	"Would you be surprised if this patient were still alive in 6 months' time?"	Yes	3
		No	0
Domain 2	Expected outcome of current treatment directed at the disease and burden of this treatment		
2.1	Expected outcome of treatment directed at the disease	There are no treatments currently that can cure the disease or prolong life.	4
		Current treatment patient is receiving or will be receiving may cure the illness.	0
2.2	Burden of treatments	Treatments carry a high level of burden (many side effects).	2
		Treatments carry no or minimal burden (side effects) or no treatment is envisioned.	0
Domain 3	Performance status		
3.1	Current performance status (in comparison with the child's own baseline)	Moderate to severe restriction of play (no active play, requires assistance for quiet play) 0-40% of normal range.	3
		Mild to moderate restriction of play (able to engage in some active play; requires assistance) 50-70% of normal range.	1
		Normal range of play (able to carry on usual play activities) 80-100% of normal range.	0
3.2	Rate of decline of performance status	Overall, performance has decreased by half over the last 4 weeks.	2
		Overall, performance has decreased by about a third over the last 4 weeks.	1
		Overall performance has not deteriorated over the last 4 weeks.	0
Domain 4	Symptom and problem burden		
4.1	Number of symptoms	Patient has 3 or more symptoms (e.g., pain, weight loss, fatigue, dyspnoea, nausea & vomiting, depression, anxiety)	4
		Patient has 2 symptoms	3
		Patient has 1 symptom	2
		Patient is asymptomatic	0

Continued.

Domain and item number	Item	Characteristics	Score (preliminary)
4.2	Symptom intensity As perceived by the parents	Any symptom is severe (equivalent to >6 out of 10)	3
		Any symptom is moderate (equivalent to 4-6 out of 10)	2
		Any symptom is mild (equivalent to 3 or less out of 10)	1
		Symptoms are absent	0
4.3	Psychological distress of patient	Significant	2
		Mild to moderate	1
		Absent	0
4.4	Psychological distress of parent(s)	Significant	2
		Mild to moderate	1
		Absent	0
4.5	Psychological distress of siblings	Significant	2
		Mild to moderate	1
		Absent	0
Domain 5	Preferences of patient, family and health professional		
5.1	Request by patient and family	Patient specifically requests a palliative care approach.	4-yes
			0-no
		Family specifically requests a palliative care approach.	4-yes
			0-no
5.2	Preference of health professional	You feel that this patient would definitely benefit from a palliative care approach.	4-yes
			0-no
		Total score	