ORIGINAL ARTICLE

Prognostic Factors in Pediatric Palliative Care: Development of a Survival Predicting Score

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ABSTRACT

OBJECTIVE: To identify prognostic factors that predicts survival in children and adolescents in palliative care. MATERIAL AND METHODS: 87 children referred to the pediatric palliative care team were evaluated for social demographic, clinical, and laboratory variables. RESULTS: A prognostic score was developed in 49 patients based on a final model, which included the following variables: diagnosis, anemia, home care provider and patient's (PPS) score given by home caregiver. The sum of the single scores has given an overall score for each patient and was used to subdivide the study population into three groups, with different probability of 60-day survival: (1) Group A: survival probability 84.4%; (2) Group B: survival probability 57.8%; (3) Group C: survival probability 15.4% (p<0.001). CONCLUSION: A pediatric palliative care score based on easily accessible variables proved to be statistically significant (p<0.05) in a multivariate analysis. The score is valid to this population. Factors that help multidisciplinary team to predict the life expectancy enable adequate information to be given to patients and families participating in therapeutic decision-making issues.

Key words: Palliative care. Pediatric. Neoplasms.

INTRODUCTION

Despite the advances in pediatric oncology and the technological resources available for treating childhood cancer, about 25 percent of children with cancer eventually die of their disease. End-of-life issues are very difficult to evaluate due to the heterogeneity of the group.[1]

Improving the ability to estimate patient length of survival may improve patients´ and their families' quality of life.[2,3]

No consensus exists about prognostic factors. Many clinical, biological, and social demographic variables have been described as predictor factors but social cultural differences may interfere.[2] A defined program has been developed in our department to address the best quality of life for the patient and his family.[4] Our palliative care program includes an interdisciplinary team approach (pediatric oncologist, nurse, psychologist, psychiatrist, social worker, physical therapist, nutritionist, specialists in pain control), coordinated by a nurse exclusively dedicated to meet patients' and families' needs and wishes. The team together with the home care provider develops a comprehensive therapeutic plan with special attention to symptoms control. To identify variables that determine the length of survival helps to prepare the patient and his family through the palliative care period until death, by appropriately allocating resources to relieve suffering. The present study describes the factors associated with the length of survival and the development of a simple prognosis score.

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MATERIAL AND METHODS

The Pediatric Department of the Cancer Hospital - São Paulo, Brazil, has a defined program in palliative care with a multidisciplinary approach, coordinated by a pediatric oncology nurse. From May 1999 to December 2001, 87 consecutive children referred to this team were followed and evaluated, according to Institutional Ethics Committee. No patients were excluded. All the information was recorded by the nurse and the physician on a model specifically designed for the palliative care group. Data were analyzed using SPSS 10.0 program.

Variables included:

Gender, age, race, religion, health insurance, home caregiver (family member), family composition, attendance to school, patient and home caregiver educational background.

Diagnosis, play performance status score - PPS (Lansky[5] or Karnofsky[6]), laboratory tests, palliative treatment proposed

Patient's play performance status (PPS) scale was assessed from the physician's, nurse's, home care providers' and patients themselves' perspectives.

STATISTICAL ANALYSIS

Survival time was measured from the date of patient's enrolment in the palliative care team to the date of his death. Survival analysis was performed through Kaplan-Meier method and the comparison of survival curves was based on log-rank test.

The prognostic factors (with p value < 0.20) identified in the univariate analysis were then evaluated in a multivariate analysis using the Cox model. In order to obtain a prognostic score model, the value of each regression coefficient was divided by the smallest regression coefficient and results were added 0.5 or 1.5. The total score for a given patient was obtained by adding together his appropriate partial scores, so the sum of the single score gave the overall score for each patient and was used to subdivide the study population into 3 groups according to tercil with specific probability of 60-day survival. Regarding the play performance status (PPS) score given by the physician, by the nurse and by the home care provider we performed an analysis of the concordance between these scores using Weighted Kappa.[7]

RESULTS

Forty-seven patients were male (54.0%), 57(65.5%) white, with age ranging from 16 months to 22-year old, mean age of 11-year old. Mothers were the care provider in 86.2% of the cases. Regarding religion, 50.6% were catholic and 27.6% evangelic. The majority of the patients had government insurance. Regarding daily activities only 10.3% were going to school. Seventeen patients had leukemia or lymphoma, 7 brain tumor and 63 solid tumor (5 with second tumors). The play performance status (PPS) was accessed by the physician, nurse and home caregiver according to the Lansky scale[5] for children from 0 to 16 year-old and Karnofsky scale[6] for children older than 16-year old. Anemia was defined as a hemoglobin level lower than 8.0 g/dl. Twelve in 65 patients had anemia, and main symptom was pain presented by 57 out of 87 patients.

Median survival was 2.6 months (range from 1 day to 28 months) and 16 of 87 patients were still alive by or on December, 2001. Among 35 variables we have identified, those with statistical significance (p<0.20) in a univariate analysis. Social demographic, clinical and laboratorial variables associated with the length of survival are described in Table 1.

The factors identified in the univariate analysis were: age, religion, home care provider, attendance to school, diagnosis, hemoglobin level < 8.0g/dl, platelet count < 50 000/mm[3], PPS given by the physician, nurse and home care provider and pain. An exponential regression model was used to investigate the independent effect of each putative prognostic factor, adjusted for all factors included in the model. The factors independently associated with the length of survival were: diagnosis (leukemias/ lymphomas or solid/central nervous system tumors), home care provider (the mother or other person), anemia (hemoglobin level less than 8.0g/dl) and PPS score given by the home care provider. The final score for a given patient was obtained by summing his/her partial scores. The final score ranged from 0 (no variables altered) to 6.5 (all variables maximum altered), demonstrated in Table 2. When the final score was 0, patients (16/49) were classified in group A (60-day survival rate of 84.4%); when the final score was between 1.0 and 1.5, patients (17/ 49) were classified in group B (60-day survival

Table 1 – Social demographic, clinical and laboratory variables associated with the length of survival. Cancer Hospital – São Paulo, May 1999 – December 2001

Variable	Category	HRb	CI95%	p
Age	= or < 5 years	1.92	1.02-3.60	0.170
	6 to 10 years	1.31	0.67-2.56	
	11 to 15 years	0.95	0.49-1.84	
	= or >16 years	1.00		
Religion	Evangelic	1.00		0.078
	Catholic	1.71	0.94-3.12	
Home caregiver	Mother	1.00		0.047
	Other	1.90	1.01-3.57	
Attendance to school	Yes	1.00		0.057
	No	2.46	0.98-6.20	
Diagnosis	Solid or CSN tumors	1.00		0.042
	Leukemia/lymphoma	1.84	1.02-3.30	
Hemoglobin level	> 8.0g/dl	1.00		0.001
	< 8.0g/dl	3.49	1.69-7.21	
Platelets count	> 50 000/mm³	1.00		<0.001
	< 50 000/mm³	3.27	1.71-6.25	
PPS Physician	100-80	1.00		0.005
	70-20	1.01	0.36-2.87	
	10-0	2.34	0.79-6.92	
PPS Nurse	100-80	1.00		0.018
	70-20	0.43	0.15-1.22	
	10-0	0.84	0.29-2.42	
PPS Home caregiver	100-80	1.00		0.003
	70-20	0.10	0.03-0.39	
	10-0	0.16	0.04-0.63	
Pain	No	1.00		0.026
	Yes	1.80	1.07-3.04	

Table 2 – Maximum likelihood estimation of regression coefficients, their standard errors, partial scores for categories of prognostic factors, and classification of patients in three risk groups. Cancer Hospital – São Paulo, May 1999 – December 2001

Variable	Category	b	SE (b)	p	POINTS
Diagnosis	Solid or CNS Tumors	0.0	-	-	0
	Leukemias/Lymphomas	1.2	0.41	0.004	1
Hemoglobin	> 8.0g/dl	0.0	-	-	0
Level	< 8.0g/dl	1.1	0.45	0.012	1.5
Home	Mother	0.0	-	-	0
caregiver	Others	0.9	0.48	0.045	1
PPS given by	100-80	0.0	-	-	0
the home	70-20	0.8	0.39	0.034	1
caregiver	10-0	2.1	0.72	0.003	2.5

Risk Groups			Total Score
A	60-day survival probability = 84.4%		0
B	60-day survival probability = 57.8%		1.0 – 1.5
C	60-day survival probability = 15.4%		2.0 – 6.5

of 57,8%) and patients (16/49) with final score between 2.0 and 6.5 were classified in Group C (60-day survival rate of 15.4%).

For example, for a child with Ewing sarcoma (0) without anemia at the acceptance to palliative care team (0), PPS given by the care provider, the mother (0), between 100-80 (0), the sum of the singles scores is 0 (Group A). A second child with retinoblastoma (0) has anemia at the acceptance to palliative care team (1.5), PPS given by the care provider, the mother (0), between 100-80 (0) with resultant sum of the singles scores 1.5 (Group B). A third child with leukemia (1.5) has anemia at the acceptance to palliative care team (1.5), EPS given by the care provider, the father (1.0), between 10-0 (2.5). The sum of the singles scores is 6.5 (Group C). Figure 1 demonstrates that patients classified in the three risk groups had a very different survival experiences.

To better understand the difference between the PPS given by the physician, the nurse and the home care giver and its impact on survival, we used the Kappa and weighted Kappa test[7] with Landis & Koch criteria[8] to evaluate the agreement.
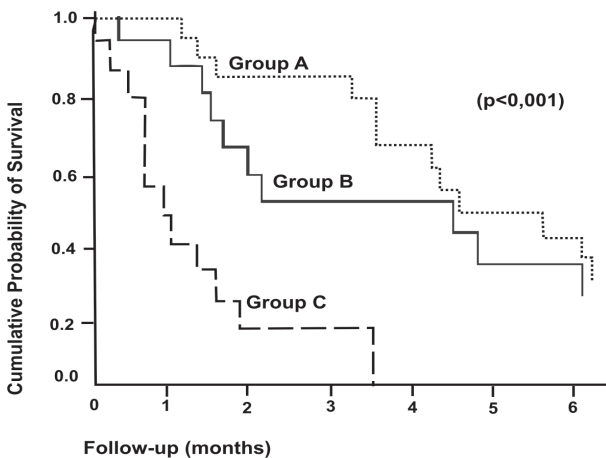

Figure 1 – Specific survival according to groups A, B and C. Cancer Hospital – SP, May 1999 – December 2001

There was substantial agreement between the PPS given by the physician and by the home care giver in 67/87 patients (Table 3).

There was almost perfect agreement between the PPS given by the nurse and by the home caregiver in 67/87 patients (Table 4), and the PPS given by the physician and by the nurse in 100% of the cases (Table 5).

Table 3 – Agreement between play performance scale (PPS) score given by the physician and by the home caregiver. Cancer Hospital – São Paulo, May 1999-December 2001

Home caregiver PPS	Physician PPS			
	100-80	70-20	10-0	Total
100-80	38	2	0	40
70-20	5	15	3	23
10-0	0	3	1	4
Total	43	20	4	67

Kappa = 0.62
Weighted Kappa = 0.74 Substantial agreement

Table 4 - Agreement between play performance scale score (PPS) given by the physician and by the home caregiver. Cancer Hospital –São Paulo, May 1999-December 2001

Home caregiver PPS	Nurse PPS			
	100-80	70-20	10-0	Total
100-80	40	0	0	40
70-20	4	18	1	23
10-0	0	2	2	4
Total	44	20	3	67

Kappa = 0.79
Weighted Kappa = 0.82 Almost perfect agreement

Table 5 - Agreement between play performance scale score (PPS) given by the physician and by the nurse. Cancer Hospital – São Paulo, May 1999-December 2001

Physician PPS	Nurse PPS			
	100-80	70-20	10-0	Total
100-80	49	1	0	50
70-20	2	27	1	30
10-0	0	2	5	7
Total	51	30	6	87

Kappa = 0.87
Weighted Kappa = 0.90 Almost perfect agreement

DISCUSSION

High-quality palliative care is now the primary goal of multidisciplinary team for patients who cannot achieve cure. The gold standard is to offer a comprehensive care coordinating different team skills to meet find patient and family needs, particularly when focusing on suffering alleviation and on promoting better quality of life. Nurses play an essential role to achieve this goal by orienting and supporting patients and families to overcome this phase. Educational aspect in nursing care requires an understanding of the theoretical background, methodology for improvement by using research findings and

personal interaction such as involvement, empathy, and understanding.

Wolfe et al.,[9] have described the substantial suffering of children with cancer at the end of life, primarily due to inadequate care by the multidisciplinary team. This report has guided us to improve care in our hospital. The factors identified in this study are easily accessible and need no special skills to apply in patients. When the cure is not possible patients want to be listened, cared and not feeling neglected. Their suffering is mainly due to unawareness, even a disagreement among physicians and families regarding the symptoms and complaints, which can be easily assessed.

Knowing the factors that help the multidisciplinary team to predict life expectancy allows the gathering of adequate information and assistance to be given to patients and families in order to participate in decision-making therapeutic issues. The development of score models predicting survival is described in the literature for adults.[10] In the pediatric field, it is still a challenge to identify the factors involved and the impact of a palliative care model.

There is no consensus on prediction of survival in patients with advanced cancer. Chow et al.[1] have shown the enormous variety on prognostic factors studied by many researchers. The identification of such factors is a great challenge, particularly in developing countries like ours. There is an enormous cultural and economical contrast among our populations, which may interfere in allocating resources for the assistance.[11] Recognizing the survival probability of a specific child may help us to plan a better care and help the family overcome this phase.

For professionals involved in care the identification of prognostic factors even in palliative care would provide time to understand the loss of a patient. For example, according to our score, a child diagnosed with leukemia/lymphoma and anemia is at high risk (Group C) and so the family will need preparation, information and training sooner than a child whose mother was the home caregiver and who had a better PPS score given by the home caregiver including him at low risk group (A). Those data give us more time to prepare them.

The classification of patients in homogeneous risk groups would help us to improve care strategies therapeutically and better allocate local resources, prepare the patient, the family and the multidisciplinary team through this phase and even be useful on inclusion criteria for phase I and phase II studies.[12]

Clinical prediction is widely described as a predictor of survival. We have not included this item in our evaluation due to the ongoing experience of starting a palliative care team. We have chosen to use the play performance status scale because of its availability and ease of understanding by the patient and home care provider. Our data suggests that the PPS is especially useful for home care providers as their PPS was significantly associated with length of survival. For multidisciplinary team it might be useful to aggregate other techniques as clinical survival prediction, symptoms/complaints, other clinical, laboratorial, and disease-related variables. Despite the small number of patients diagnosed with CNS disease, our data suggests a disagreement between home caregiver and multidisciplinary team scores. These findings show a possible ability of the home caregiver in better evaluating small changes in the patients' status. Professionals may find difficulties in using PPS for scoring patients with a neurological or cognitive degeneration.

Despite the lack of formal courses and education regarding palliative care in our medical and nursing schools, as in many countries as shown by Rabow et al.,[13] and Billings and Block,[14] we found out that the novice professionals have a stimulating interest in this topic. The lack of experience is replaced by the motivation for learning how to better take care of a dying child and assist the family. Some feelings of impotence and failure are balanced with feelings of professional accomplishment.

The created score model is valid in this population and a prospective series of patients is required. It has been used in a prospective manner to help nurses to better prepare children, family and staff on coping with the end-of-life issues.

The primary task of the multidisciplinary team for patients in palliative care and their families is to offer comfort and dignity by incorporating palliative care assistance. To

identify prognostic factors in advanced childhood cancer and to improve these techniques to predict survival in terminal pediatric cancer patients is the first step towards an effective care to the patient and his family in such a difficult period.

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