Residência RP Pediátrica
Publicação Oficial da Sociedade Brasileira de Pediatria
ISSN-Online: 2236-6814

Submitted on: 06/28/2020
Approved on: 07/17/2020

ORIGINAL ARTICLE

Palliative care eligibility for pediatric inpatients seen at a teaching hospital

Giulia Cardoso Masotti[1], Antonia Teresinha Tresoldi[1]

Keywords:
palliative care, palliative medicine at the end of life, pediatrics.

Abstract

Objectives: To quantify the proportion of pediatric inpatients eligible for palliative care at the teaching hospital of the University of Campinas (HC/UNICAMP). **Methods:** This retrospective descriptive cross-sectional study included pediatric inpatients seen at HC/UNICAMP from June to October 2017. Patients were deemed eligible if they had one of the following underlying conditions at the time of admission: (I) diseases for which curative therapy exists, but may fail; (II) diseases in which premature death is expected, but for which comprehensive care may prolong life with reasonable quality; (III) chronic progressive diseases for which only palliative, potentially prolonged, care is available; (IV) non-progressive neurological disorders that increase the likelihood of premature death. Patients deemed eligible were compared to non-eligible patients based on sex, age, type of admission (emergency/elective), and frequency of readmission. P-values below 0.05 were considered statistically significant. **Results:** Almost a third (30.9%) of the pediatric inpatients seen at HC/UNICAMP were deemed eligible for palliative care. The demographic profiles of eligible and non-eligible patients were not significantly different. The number of readmissions and emergency admissions of eligible patients was significantly greater than that of non-eligible patients. **Conclusion:** Although challenging, this is a subject that requires more discussion to further improve the overall care provided to pediatric patients.

[1] University of Campinas, Pediatrics – Campinas, São Paulo, Brazil.

Correspondence to:
Giulia Cardoso Masotti.
Universidade Estadual de Campinas. Cidade Universitária Zeferino Vaz - Barão Geraldo, Campinas - SP. Brazil. CEP: 13083-970. E-mail: giuliamasotti@gmail.com

DOI: 10.25060/residpediatr-2022.v12n2-359

This work is licensed under a Creative Commons Attribution 4.0 International License.

INTRODUCTION

Epidemiologic transition is the process by which incidence or prevalence of disease and causes of death change over time. Morbimortality patterns may work as relatively sensitive indicators of the living conditions and the developmental framework of a given population, and reflect the outcome of a number of interdependent factors[1].

Recent developments in science and technology have played a key role in the changes seen in population disease profiles. With more comprehensive and effective care, the number of patients with chronic disease and survival have both substantially increased, producing a new population of patients: children, adolescents, and adults with complex medical conditions for which there is no cure, with growing life expectancy[1-6].

Clearly demonstrated in adult populations, this trend has also affected pediatric patients and gradually changed the type of individuals that seek pediatric care all over the world: from patients affected predominantly by acute conditions to chronically ill subjects requiring hospitalization for indefinite periods of time or numerous admissions to treat complications stemming from their underlying conditions.[5,6]. In the United States, about 55,000 children and adolescents aged 0-19 years die annually of complications from noncommunicable diseases (NCDs), thus corroborating the relevance of providing care to pediatric patients with chronic, degenerative diseases[7].

Healthcare systems adjust slowly and gradually in Brazil and abroad[1-4]. However, the most significant challenge imposed by this novel scenario is the adjustment patients and their families need to go through as they live with a chronic disease, potentially stable for many years, for which premature death is the most likely outcome.

In addition to ethical and medical dilemmas, the new reality of inpatient care creates a series of economic implications. Keeping patients in hospital for indefinite lengths of time on intensive or semi-intensive care requires unprecedented amounts of supplies, human and financial resources. In the United States, the equivalent to 18% of the GDP is spent annually with healthcare, yielding an annual *per capita* cost of USD 8,000. A quarter of these resources are spent in the last year of life and about 9% in the last month of life of the patient. In the United Kingdom, Portugal, and the Middle East, for example, the main driving force behind healthcare cost increase is the significant surge in the number of hospitalizations and hospital deaths, which has brought the spending with beds, staff, and supplies to an unsustainable level[6, 7].

The care provided to patients with chronic diseases is delivered at different levels of complexity – from outpatient management of symptoms and distress manifested by patients, their families, or caregivers, to the management of complications from disease in a hospital setting[5-7].

Palliative care is designed to improve the quality of life of patients and families facing diseases that threat the continuation of their existence together. To do so, it requires an impeccable assessment and management of not only pain, but all symptoms of a physical, social, emotional, and spiritual nature affecting patients and their loved ones[6, 8-9]. The management of ethical, spiritual, and physical symptoms resides in the core of palliative care and permits a horizontal and thorough contemplation of the distress patients and their families experience when faced with the finitude of life[8-10].

Due to the growing demand for care from patients with chronic disease, the 2014 issue of the Global Strategy for the Prevention and Control of NCDs of the World Health Organization (WHO) described palliative care as one of the top-12 topics in the global healthcare agenda and stressed the importance of defining and funding interventions at a national level to strengthen palliative care capabilities[8,11].

Nevertheless, when asked about palliative care, people from most cultures prefer to spend their last days and die at home, without unnecessary or aggressive interventions devised to pointlessly prolong their lives. Interestingly, the barriers to implementing palliative care include lack of discussions about the subject by care teams; feeding false hopes and not confronting patients and families with the realities of the disease; and lack of mechanisms to transition from curative to palliative care[6-7,10].

An offshoot of the impossibility to provide palliative care, therapeutic obstinacy – the prescription of disproportionate care measures to patients irrevocably faced with death – imposes distress and pain on patients all over the world. Characterizing care measures as therapeutic obstinacy is no simple task. Therapies deemed ordinary for some cases may be excessive in others, and the line that separates needed from futile care is thin and even blurred in the eyes of healthcare workers and families. This is why each case must be assessed individually and thoroughly[12-14].

One of the main barriers to defining and accepting certain care measures as dysthanasia and to replace curative with palliative care is the prognostic uncertainty that surrounds most diseases, particularly pediatric ones[9]. The discomfort families and caregivers feel when confronted with the decision to suspend or postpone treatment that has been considered ineffective or futile may be soothed by the comprehension that a therapeutic boundary has been reached, and that the continuation of care will no longer produce medical benefit. The definition of such therapeutic boundary must be made jointly and accepted by healthcare workers and families, and may change depending on patient medical developments. Despite the knowledge held by medical teams, decisions about therapy cannot be made unilaterally[9,13-15].

In this context, healthcare teams face an ethical and moral issue: the conflict between providing care instead of a cure to patients and questions around how much and the type of care that should be reasonably offered to patients

with limited life expectancy[6]. This discussion must be guided by the four principles that govern medical work: autonomy; beneficence; nonmaleficence; and justice. In addition, healthcare workers cannot be forced to participate in care measures with which they do not agree or are in a moral conflict with[6,10].

In the realm of Pediatrics, the issues discussed above gain renewed complexity. Ethical nuances deserve particular attention, since the autonomy of pediatric patients is hindered in most cases and parents/guardians are often unable to make decisions about the health of their children on their behalf; nonetheless, the basic ethical principles of beneficence, nonmaleficence, and justice still apply to every patient[9]. The differences between adult and pediatric patients do not reside only within ethics, but in the cognitive limitations and low levels of maturity present in children and adolescents and the peculiar way they face disease and terminality; in the epidemiology of disease and death in each age range; in the support network and decision-making process associated with care; in the way function is defined based on age; and in the impact of age on treatment decisions[7,9-10]. Above all aforementioned issues lies the taboo concerning disease and death of children, intensely present in the collective unconscious and the minds of healthcare teams used to managing critical pediatric patients[6,16]. One should note that, in the care of pediatric patients, the use of invasive and life support measures is acceptable even in the final moments and does not imply in palliative care failure, as long as such measures have been discussed and agreed upon by the healthcare team, the family, and the patient; palliative care must be installed gradually and not upon the immediate removal of curative therapy, but rather as an alternative when the patient's clinical condition has become irreversible[7,9-10,16].

This study aimed to quantify the proportion of patients deemed eligible for palliative care from the group of pediatric patients seen at HC/UNICAMP from June to October 2017. Secondary objectives include the description of the epidemiologic profile of inpatients (age and sex), type of admission (emergency or elective), and frequency of readmissions of eligible versus ineligible patients during the study period.

METHODS

This retrospective descriptive cross-sectional study included inpatients seen at the Pediatrics Ward of a teaching hospital.

The study was carried out in a ward with 36 beds for pediatric patients aged 0-14 years at a tertiary referral hospital; four beds are set aside for Nephrology patients, three for Pediatric Surgery, and the rest is shared by patients coming from the Emergency Unit, the Intensive Care Unit (ICU), and wards from other medical specialties.

Qualitative and quantitative data of all patients staying at the Pediatrics Ward were collected from the hospital's information system. Data collection began after the hospital's Research Ethics Committee approved the study design.

The patients were split into groups of eligible and non-eligible individuals. Eligibility for palliative care was determined based on the underlying disease patients had on admission. Individuals with one or more of the conditions listed below were deemed eligible:[10,16]

1. Diseases for which curative treatment is possible, but may fail:
   a. Progressive cancer, advanced cancer, or cancer with poor prognosis;
   b. Complex congenital/acquired heart disease.
2. Diseases in which premature death is expected, but for which comprehensive care may prolong life with reasonable quality:
   a. Cystic Fibrosis;
   b. HIV/AIDS;
   c. Chronic diseases or malformations of the gastrointestinal tract;
   d. Severe epidermolysis bullosa;
   e. Immunodeficiency;
   f. Non-dialysis chronic kidney disease/without indication or possibility of transplantation;
   g. Chronic respiratory failure flare-up;
   h. Muscular dystrophy.
3. Chronic progressive diseases for which only palliative, potentially prolonged, care is available:
   a. Mucopolysaccharidosis and other deposit diseases;
   b. Chromosomal anomalies;
   c. Osteogenesis imperfecta.
4. Non-progressive neurological disorders that increase the likelihood of premature death:
   a. Severe cerebral palsy with recurrent infection;
   b. Neurologic sequelae of infectious diseases;
   c. Hypoxia / anoxia wit brain injury;
   d. Holoprosencephaly / other malformations.

For purposes of comparing between groups, the following data were collected:

- Age (in full years):
  - Patients were categorized as infants (children aged < 2 years); preschoolers (children aged between two and less than five years); school-age children (aged between five and less than 11 years); or adolescents (aged between 11 and 19 years), as stipulated in the categories defined by the Brazilian Society of Pediatrics[17].
- Sex;
- Readmissions during the study period;
- Type of admission (emergency or elective).

Statistical Analysis:

Numerical variables were expressed as mean values, standard deviations (SD), and median values. The associations between variables and factors of interest were verified with

Student's t-test for samples with a normal distribution. In non-normal distributions, the associations were assessed with Mann-Whitney's test. Qualitative variables were expressed as absolute (n) and relative (%) frequencies. The chi-squared test ($\chi 2$) was used to analyze potential associations between these variables and factors of interest.

P-values below 0.05 were deemed statistically significant. All tests were run on statistical software package SAS version 9.4 (SPSS, Cary, NC, USA)[18,19].

The authors of this study have committed to safeguarding the confidentiality of participant data.

RESULTS

A total of 436 patients stayed at the Pediatric Ward during the study period, and 135 (30.9%) were deemed eligible for palliative care.

There was a predominance of male patients (58.3%) and emergency admissions (59.9%). Inpatient mean age was 4.5 years (median 3.0 years).

Twenty-three eligible patients (17%) had to be readmitted during the study period, as seen in Table 1. There was a predominance of male individuals (54.8%) and emergency admissions (51.9%). Patient mean age was 4.9 years, as seen in Table 2.

Table 1. Comparison of proportion of readmission and type of admission between groups.

	Total (n)	Readmissions (n / %)	Type of admission (n / %)
All patients	436	47 (10.8%)	Emergency 261 (59.9%) Elective 175 (40.1%)
Eligible patients	135	23 (17.0%)	Emergency 70 (51.9%) Elective 65 (48.1%)

Table 2. Comparison of demographic data between groups.

	Age	Sex (n / %)
All patients (n= 436)	4.5 ± 4.7	Female 182 (41.7%) Male 254 (58.3%)
Eligible patients (n= 135)	4.9 ± 5.0	Female 61 (45.2%) Male 74 (54.8%)

Infants accounted for most of the patients admitted to the ward during the study period, with a total of 182 individuals (41.7%). An average of 107 patients were admitted per month, with July having the highest number of admissions.

Among the conditions listed as reasons to prescribe palliative care, neurological disorders stood out as the most common, with 42 patients (31.1%), as seen in Table 3.

Table 3. Distribution of patients eligible for palliative care by group of diseases.

	Total (n)	Total (%)
Group 1	39	28.89%
Group 2	36	26.67%
Group 3	18	13.33%
Group 4	42	31.11%

Legend: Group 1: Diseases for which curative treatment is possible, but may fail; Group 2: Diseases in which premature death is expected, but for which comprehensive care may prolong life with reasonable quality; Group 3: Chronic progressive diseases for which only palliative, potentially prolonged, care is available; Group 4: Non-progressive neurological disorders that increase the likelihood of premature death.

The parameters shown in Table 4 had p-values <0.05 and were considered statistically significant.

Table 4. Statistically significant variables.

ADMISSION	NON-ELIGIBLE	ELIGIBLE	Total (n / %)	*p*
ELECTIVE				
No	193 (64.1%)	70 (51.9%)	263 (60.3%)	0.015519
Yes	108 (35.9%)	65 (48.1%)	173 (39.7%)	
EMERGENCY				
No	110 (36.5%)	65 (48.1%)	175 (40.1%)	0.022319
Yes	191 (63.5%)	70 (51.9%)	261 (59.9%)	
READMISSION				
No	277 (92.0%)	112 (83.0%)	389 (89.2%)	0.004819
Yes	24 (8.0%)	23 (17.0%)	47 (10.8%)	

DISCUSSION

Our study touched briefly on a broad and complex matter pertaining to healthcare, specifically in what concerns the care provided to pediatric patients with chronic or life-threatening disease. The WHO has stated that palliative care should be provided to every pediatric patient with clinical conditions that limit quality of life or life expectancy, based on local resources and peculiarities[8, 11].

There is little information in Brazilian literature to support a comparison between the epidemiological profiles of pediatric patients seen in teaching hospitals. A study conducted in the State of Santa Catarina in 2001 found that infants accounted for most admissions of pediatric patients, as also seen in our study[20]. This finding might be partially attributed to the seasonality of respiratory virus infections, which peak in the months of March to July in the State of São Paulo, although infants with respiratory distress requiring hospitalization were also admitted in the fall and spring in this study[21-22].

Our study showed that a considerable portion of the patients seen in the Pediatrics Ward – about 30% – met the criteria for palliative care eligibility. Parente et al.[23] looked into the clinical and epidemiological profiles of patients admitted to a pediatrics ward of a teaching hospital in the State of Ceará between August and December of 2015 and found that 48.1% of the patients had chronic disease and 25.2% had a history of prior admission. A similar study conducted in 2008 in Rio de Janeiro included patients seen at four hospitals in the State and found that 47.6% of the patients had chronic disease and 35.3% had a history of readmission[24]. In addition to the high number of readmissions, these findings are similar to the ones published in our study in the sense that patients with this clinical profile are preferentially treated at high complexity centers, and in the considerable prevalence of pediatric patients with chronic disease[23-24].

The patients deemed eligible for palliative care in our study had more emergency admissions due to acute complications or decompensated underlying disease, which have been associated with worse quality of life, increased personal and family distress, and substantial increases in the cost of public healthcare. The facts described in this study clearly indicate that the provision of horizontal, linear care to patients with chronic disease in inpatient and outpatient settings may improve the overall quality of the care provided to them[6-7, 9].

The study also showed that patients eligible for palliative care are hospitalized more frequently to undergo surgery or procedures related to their underlying conditions than their non-eligible counterparts. This finding is supported by current literature about the peculiarities of care delivered to patients with chronic disease and the longitudinal and multidisciplinary character of such care[9-10, 15-16]. In addition, our study found a greater proportion of patients with neurological disorders in the group eligible for palliative care.

The limitations of this study include the short period of time considered in our analyses, the fact that our hospital is a high complexity referral center for cystic fibrosis, congenital heart disease, pediatric airway conditions, nephrology, and neurosurgery, which substantially changes the profile of patients seen in the average pediatrics ward in Brazil. In addition, the patients were assessed only briefly, based solely on their underlying conditions as a criterion for palliative care eligibility. Acute events that might potentially alter patient prognosis, such as meningitis or severe head trauma, were not considered in the assessment of eligibility and might have led to an underestimation of the number of patients eligible for palliative care.

Further studies are needed to strengthen and promote the delivery of proper care to pediatric patients with chronic and life-threatening conditions in Brazil. Although challenging, this is a subject that requires more discussion to further improve the overall care provided to pediatric patients, considering the individuality of each patient in all aspects of their disease and while facing death as a possibility[25].

REFERENCES

1. Prata PR. The epidemiologic transition in Brazil. Cad Saúde Pública. 1992 Jun;8(2):168-75.
2. Brito F. Transição demográfica e desigualdades sociais no Brasil. Rev Bras Estud Popul. 2008 Jun;25(1):5-26.
3. Schramm JMA, Oliveira AF, Leite IC, Valente JG, Gadelha AMJ, Portela AMC, et al. Transição epidemiológica e o estudo de carga de doença no Brasil. Ciênc Saúde Colet. 2004 Dez;9(4):897-908.
4. Barreto ML, Carmo E. Mudanças em padrões de morbi-mortalidade: conceitos e métodos. In: Monteiro C, org. Velhos e novos males da saúde no Brasil. São Paulo: Hucitec; 1995. p. 17-30.
5. Goldani MZ, Mosca PRF, Portela AK, Silveira PP, Silva CH. Impacto da transição demográfico-epidemiológica na saúde da criança e do adolescente do Brasil. Rev HCPA. 2012;32(1):49-57.
6. Brito MA, Soares EO, Rocha SS, Figueiredo MLF. Cuidados paliativos em pediatria – um estudo reflexivo. Rev Enferm UFPE. 2015 Mar;9(3):7155-60.
7. Himelstein BP, Hilden JM, Boldt AM, Weissman D. Pediatric palliative care. N Engl J Med. 2004 Abr;350(17):1752-62.
8. Moritz RD, Lago PM, Souza RP, Silva NB, Meneses FA, Othero JCB, et al. Terminalidade e cuidados paliativos na unidade de terapia intensiva. Rev Bras Ter Intensiva. 2008;20(4):422-8.
9. Collins JJ, Campbell K, Edmonds W, Frost J, Mherekumombe MF, Samy N. Care of children with advanced illness. In: Cherny N, FallonM, Kaasa S, Portenoy RK, Currow DC, eds. Oxford textbook of palliative medicine. Oxford: Oxford University Press; 2015.
10. Hauer J, Poplack DG, Armsby C. Pediatric palliative care [Internet]. Boston: UpToDate; 2022; [acesso em 2018 Set DIA]. Disponível em: https://www.uptodate.com/contents/pediatric-palliative-care?search=pediatric%20palliative%20care&source=search_result&selectedTitle=1~19&usage_type=default&display_rank=1
11. World Health Organization (WHO). National cancer control programmes: policies and managerial guidelines. 2ª ed. Geneva: WHO; 2002.
12. Diniz D. Quando a morte é um ato de cuidado: obstinação terapêutica em crianças. Cad Saúde Pública. 2006;22(8):1741-8.
13. Pessini L. Distanásia: até quando investir sem agredir? Rev Bioét. 1996;4(1):31-43.
14. Miller-Smith L, Lantos JD, Pope TM, Arnold RM, Givens J. Palliative care: medically futile and potentially innapropriate therapies of questionable benefit [Internet]. Misouri: UpToDate; 2020; [acesso em 2018 Set DIA]. Disponível em: https://www.uptodate.com/contents/palliative-care-medically-futile-and-potentially-inappropriate-therapies-of-questionable-benefit
15. Fraser J, Harris N, Berringer AJ, Prescott H, Finlay F. Advanced planning in children with life-limiting conditions – the Wishes Document. Arch Dis Child. 2010 Fev;95(2):79-82.
16. Sociedade Brasileira de Pediatria (SBP). Departamento Científico de Medicina da Dor e Cuidados Paliativos. Cuidados paliativos pediátricos: o que são e qual sua importância? Cuidando da criança em todos os momentos. Rio de Janeiro: SBP; 2017.
17. Sociedade Brasileira de Pediatria (SBP). Pediatria ambulatorial – resgate do pediatra geral. Rio de Janeiro: SBP; 2004.
18. Conover WJ. Practical nonparametric statistics. 3ª ed. New York: John Wiley & Sons Inc.; 1999.
19. Fleiss JL. Statistical methods for rates and proportions. 2ª ed. New York: John Wiley & Sons Inc.; 1981.
20. Silva ACO. Perfil nutricional das crianças internadas na enfermaria geral de pediatria do Hospital Universitário da Universidade Federal de Santa Catarina [dissertação]. Florianópolis (SC): Universidade Federal de Santa Catarina (UFSC); 2001.

21. Ministério da Saúde (BR). Nota técnica conjunta nº 05/2015 CGSCAM/DAPE/SAS/MS, CGAFME/DAF/SCTIE/MS e CGDT/DEVIT/SVS/MS. Sazonalidade do vírus sincicial respiratório no Brasil. Brasília (DF): Ministério da Saúde; 2015.
22. Salomão Junior JB, Gardinassi LGA, Simas PVM, Bittar CO, Souza FP, Rahal P, et al. Vírus respiratório sincicial humano em crianças hospitalizadas por infecções agudas das vias aéreas inferiores. J Pediatr (Rio J). 2011 Jun;87(3):219-24.
23. Parente JSM, Silva FRA. Perfil clínico-epidemiológico dos pacientes internados na clínica pediátrica em um hospital universitário. Rev Med UFC. 2017;57(1):10-4.
24. Duarte JG, Gomes SC, Pinto MT, Gomes MASM. Perfil dos pacientes internados em serviços de pediatria no município do Rio de Janeiro: mudamos? Physis. 2012;22(1):199-214.
25. Lindley LC, Nageswran S. Pediatric primary care involvement in end-of-life care for children. Am J Hosp Palliat Care. 2017 Mar;34(2):135-41.