Mortality in Pediatric Palliative Care in a Tertiary Center

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Abstract

Introduction: Complex chronic diseases have been responsible for about a third of all pediatric deaths in Portugal in recent years. Early referral and implantation of an advance care plan are strategies that result in greater preparation on the part of families for dealing with the course of illness of these children. This study aimed to characterize the mortality data of patients followed by the pediatric palliative care in-hospital support team in a tertiary center between January 2018 and June 2021.

Methods: This retrospective study was performed using the analysis of clinical files, demographic data, nosological groups, referral dates, expectations, and place of death of patients as well as the interventions carried out by the team.

Results: In total, 64 children were followed by the pediatric palliative care in-hospital support team, 25 (39%) of whom died. More than half of the children who died had neurological pathology, which was the most frequent diagnostic area. Moreover, 14 (56%) children died less than 6 months after their referral to the team. Most of the children died during hospitalization (56%), while 28% of the deaths occurred at home.

Conclusion: The collected data suggests a late referral to pediatric palliative care, which is why it is of utmost importance to invest in the creation of specialized teams at the national level and the training of health professionals in this area. The main place of death was the hospital, as in previous studies, although with an apparent increasing trend of deaths at home.

Keywords: Advance Care Planning; Cause of Death; Child; Child Health Services/trends; Child, Preschool; Chronic Disease/mortality; Hospital Mortality; Infant; Palliative Care/trends; Portugal

Keypoints

What is known:
- Pediatric palliative care consists of preventing and alleviating the suffering of children dealing with life-threatening diseases.
- There has been an increase in pediatric mortality attributable to complex chronic diseases, with these children often needing palliative care.

What is added:
- These children seem to be lately referred to palliative care, which shows the need for professionals training in this area.
- Deaths occur most commonly in hospital setting, but with an increasing trend of deaths at home.

Introduction

According to the World Health Organization, pediatric palliative care (PPC) consists of prevention and alleviation of the suffering of pediatric patients and their families, dealing with the underlying problems of life-threatening diseases.[1] Moreover, complex chronic diseases were defined as any medical condition that is expected to last for at least 12 months, with sufficient severity to require specialized pediatric care[2].

An increase in pediatric mortality attributable to complex chronic diseases has been reported in several countries. In the United Kingdom, a study conducted between 2001 and 2010 identified that 50% of pediatric deaths are attributable to complex chronic diseases.[3] In the United States of America, in 1997, complex chronic diseases accounted for 46.8% of mortalities during pediatric age.[2]

Identification of children in need of palliative care can be a challenging task. A question that may be helpful in this context is: would you be surprised if this child did not survive until the age of 18? If the answer is no, it is likely that we are facing a child who needs this type of care. There are scales that help in the identification of

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these patients, one of which is the pediatric palliative screening (PaPaS) scale,[4] whose Portuguese version was recently proposed for validation. Some entities, such as the American Academy of Pediatrics, advocate that pediatric palliative care should be instituted right at the time of the diagnosis of a life-threatening disease, and continued during its course, regardless of whether the outcome is cure or death.[5]

It is also a complex task to estimate the overall survival of a child with complex chronic diseases, which is why some studies have found it useful to categorize it into days to weeks, weeks to months, and months to years, to avoid the evocation of specific numbers, which often end up not corresponding to reality. On the other hand, some of these children present, throughout the course of their illness, episodes of clinical deterioration that make us think that their death is imminent, but from which they end up recovering.[6]

Taking into account all the uncertainty in the path of these patients, it is very important to carry out an advance care plan. This can include resuscitation plans, action plans in the face of clinical deterioration, and fulfillment of their wishes during life and posthumously.[7] This strategy has been shown to result in greater preparation on the part of families to deal with the course of the illness of these children, and a feeling that their quality of life was higher than expected during this period.[8]

This study aimed to retrospectively characterize data on the mortality of patients followed by the pediatric palliative care in-hospital support team (PPCIHST) of Hospital Santa Maria, Centro Hospitalar Universitário Lisboa Norte, between January 2018 and June 2021.

Methods

The required data were collected, including demographic data (*eg*, age and gender), diagnosis, palliative needs group, reason and date of referral to the team, family structure, main caregiver, death expectation management, place of death, anticipated care plan, resuscitation plans, support / intervention in grief, and social intervention. A descriptive statistical analysis was performed on the collected data.

Results

Based on the results, between January 2018 and June 2021, 64 children were followed by the PPCIHST. There were 25 deaths, which translates into a mortality rate of 39%. It should be mentioned that the year with the highest mortality rate was 2018 (n = 8, 32%). Moreover, the majority of patients were male (60%). Regarding the age of the diagnosis of their pathologies, most of the children were below 5 years old, while the minority of them were diagnosed between the ages of 6 and 10 years old.

In terms of the area of diagnosis, 52% (n = 13) of the patients had a neurological disease, while the remaining patients distributed heterogeneously in other areas, such as genetics, pulmonology, and cardiology, among others. It is noteworthy that only three children (12%) had an oncological diagnosis.

The family structure and the main caregiver of these children were also registered, and most of them were part of a nuclear family (n = 19, 76%), with the mother standing out as the main caregiver in most cases (n = 16, 64%).

Table 1 summarizes a more detailed characterization of the patients. Moreover, Table 2 tabulates each diagnosis and its distribution by category.

Conventionally, complex chronic diseases are categorized into four different groups (I to IV) based on the palliative needs that they entail, whose definitions are summarized in Table 3.[9] In this study, most of the children had pathologies that were categorized into groups III (36%) and IV (40%) which represent diseases that can have a relatively long course (Table 3).

The reasons for referring these children to palliative care were found to be the integration into hospital and community care, which motivated the largest number of

Table 1. Characterization of deceased patients followed by the team (n = 25)

Gender	
Male	15 (60%)
Female	10 (40%)
Age at diagnosis	
< 1 year old	11 (44%)
1-5 years old	12 (48%)
6-10 years old	2 (8%)
Family structure	
Extended family	2 (8%)
Nuclear family	19 (76%)
Single parent family	4 (16%)
Main caregiver	
Grandmother	2 (8%)
Institutionalized	1 (4%)
Mother	16 (64%)
Mother and father	4 (16%)
Father	2 (8%)

Table 2. List of diagnosis and distribution per area (total = 25)

Diagnosis area	Diagnosis (n)	Total per diagnosis area (%)
Cardiology	Dilated cardiomyopathy (1)	1 (4%)
Infectious diseases and immunodeficiencies	Hyper immunoglobulin E syndrome (1)	1 (4%)
Genetics	Polymalformative syndrome (2) 3q29 deletion syndrome (1)	3 (12%)
Hemato-oncology	Neuroblastoma (1) Aplastic anemia (1) B-cell lymphoproliferative disorder(1)	3 (12%)
Metabolic disease	Tay Sachs disease (1) Pompe disease (1) Mucopolysaccharidosis type II (1)	3 (12%)
Nephrology	Arthrogryposis-renal dysfunction-cholestasis syndrome (1)	1 (4%)
Neurology	Neurological sequelae of bacterial meningitis (1) Hypoxic-ischemic encephalopathy (5) Duchenne muscular dystrophy (2) Lipofuscinosis (1) Zelwegger disease (2) Neurodegenerative disorder under investigation (1) Leigh syndrome (1)	13 (52%)

Table 3. Palliative needs groups (n = 25)

I	Pathologies for which potentially curative therapeutic options exist, which may not be effective	3 (12%)
II	Pathologies that lead to inevitable early death, but with the possibility of long survival if undergoing treatment	3 (12%)
III	Progressive diseases without available curative therapeutic options, whose palliative treatment may need to be prolonged over several years	9 (36%)
IV	Irreversible non-progressive diseases, which lead to severe disability and possibility of premature death	10 (40%)

Adapted from Chambers L. A guide to the development of children's palliative care services. 4th ed. Bristol: Together for Short Lives; 2018.[9]

referrals (n = 11, 44%), symptomatic control (n = 8, 32%), the elaboration of an advance care plan (n = 3, 12%), family support (n = 2, 8%), and at last, provision of care at the end of life (n = 1, 4%).

As for the do-not-resuscitate order, 22 children had an advance care plan with directives for optimization of comfort care and do-not-resuscitate. In five of these children, the required document was shared with the parents; therefore, in case of deterioration of the health status of these children, the parents could provide it to the health professionals who cared for the child to put it into practice.

Regarding the support provided after referral to the team, home visits were made by the PPCIHST for 17 children (68%). Moreover, 18 (72%), three (12%), two (8%), and one (4%) children were integrated into the national long-term care network, children palliative care units, inpatient mode, and communitary mode, respectively.

Regarding the age at death, these children were divided into four age groups (< 1 year, 1-5 years old, 6-10 years old, and > 11 years old) with no significant differences between groups (Table 4). The median age at death was 5 years, with a minimum age of 3 months and a maximum age of 20 years.

The period of time between referral to PPCIHST and death was measured and categorized in the following ranges: less than two months, two to six months, six months to one year, and one to two years. It is noteworthy that six (24%) and eight (32%) deaths occurred in less than two months and two to six months after referral, respectively, which constituted 56% of deaths within a period of less than six months. The minimum period of time was two days, and the maximum was 24 months.

The most frequent place of death was the hospital followed by home, where 56% and 28% of deaths occurred, respectively. Other less frequent locations included pediatric intensive care, palliative care unit, and the emergency department.

Several types of intervention were performed in the peri-death period, which will be described later. The PPCIHST provides support to the families of the children on an almost permanent basis, in a way that they are free to contact the team members whenever they identify a problem. The clinical evolution and prognosis of each patient are taken into account for the management of the expectations and place of death. Moreover, the families are prepared and empowered for that moment, and it is tried to define the most appropriate place in an individualized manner.

The desired place of death was taken into account for all the patients and families who expressed this will (17 out of 25, six of whom died at home). In the remaining cases, it was either not possible to discuss the place of death, given that the death occurred in a short period of time, or the parents had no preference.

Whenever possible, an advance care plan is developed to define in advance which measures or procedures should or should not be adopted in the event of clinical deterioration, as well as the expressed wishes of both the parents and the children themselves. During this period, whenever possible, the team was physically present to support the family. Furthermore, it should be noted that after death, support in mourning was provided.

Table 4 summarizes the mortality data, and Table 5 tabulates the performed interventions.

Social intervention was carried out with each patient and involved emotional support, legal support, integration of the social, cultural, and religious context of each family, problem-solving training, and social support (Table 6).

Most of the time, the grieving process of parents / relatives begins when they receive the diagnosis of the life-threatening illness of the child. From that moment on, and as the disease progresses, they face a set of losses (real and symbolic) that must be recognized and attended to by the team in order to facilitate this anticipatory grief. The specialized intervention in grief at the PPCIHST begins with the first multidisciplinary consultation, in which the individual needs of each child and their family are identified.

Subsequent follow-up is carried out in form of individual and/or family consultations in an outpatient setting and the home context throughout the course of the disease and after the death. On the seventh and 30th day after death, a condolence letter and a psycho-educational manual on the grieving process are sent. On special dates, such as birthdays, holidays, or other special dates, families are contacted by telephone by a member of staff.

Table 4. Mortality data (n = 25)

Age at death date	
< 1 year old	6 (24%)
1 - 5 years old	7 (28%)
6 - 10 years old	6 (24%)
> 11 years old	6 (24%)
Period of time between referral and death	
< 2 months	
2 - 6 months	8 (32%)
< 1 year	4 (16%)
< 2 years	7 (28%)
Death place	
Hospital	14 (56%)
Home	7 (28%)
Palliative care unit	2 (8%)
Emergency service	1 (4%)
Intensive care unit	1 (4%)
Mortality per year	
2018	8 (32%)
2019	4 (16%)
2020	6 (24%)
2021	7 (28%)

Discussion

In a report published in 2014,[10] it was estimated that in Portugal, in 2013, around 6000 children had limiting or life-threatening illnesses, and as a result, needed pediatric palliative care. This report was based on a study carried out from 1987 to 2011.[11] In the aforementioned study, it was found that in that period of time, complex

Table 5. Interventions performed (n = 25)

Reason for referral	
Articulation of hospital and community care	11 (44%)
Symptomatic control	8 (32%)
Advance care planning	3 (12%)
Family support	2 (8%)
End of life care	1 (4%)
Support provided	
Articulation with the national long term care network	18 (72%)
Community palliative unit support	3 (12%)
Home visit by the hospital team	17 (68%)
Peri-death interventions	
Permanent availability of the team (24/7)	23 (92%)
Advance care plan	22 (88%)
Management of death / place of death expectations	21 (84%)
Community grief support	18 (72%)
Hospital grief support	9 (36%)
Physical presence of the team (hospital deaths)	6 (24%)

Table 6. Social intervention

• Information, guidance and streamlining of community resources.
• Emotional support and mediation.
• Activation of the formal emergency support network or other specific support, such as legal support.
• Individualized and holistic intervention (integration of family, social, cultural, religious, and spiritual aspects).
• Training for autonomy and problem solving.
• Guarantee of necessary adjusted social support.

chronic diseases were responsible for about a third of all deaths in pediatric age, and neoplastic disease was mentioned as the main cause. Moreover, one-third of these deaths occurred during the first year of life, and the median age of death was 4 years and 4 months. Regarding the place of death, most of these children (79.7%) died in a hospital and 15.6% of them died at home. Throughout the above-mentioned study, there was a decreasing trend of deaths at home and in the last year of the research, only 11.5% of children died at home.

More recently, the Portuguese palliative care observatory reported that 90 children were admitted to pediatric palliative care in 2018, the majority (90%) of whom had non-neoplastic pathology. In the aforementioned report, the mortality rate was 47.5%, with 25% of patients being discharged from pediatric palliative care. In that report, it was also estimated that there were around 8000 children with pediatric palliative care needs in the country at that time.[12]

In the present study, an overall mortality rate of around 39% was observed which was considered to be a significant rate. The highest mortality rate was observed in 2018 when the provision of PPCIHST was officially started. Moreover, there was a predominance of males (60%), and the vast majority of these children (92%) were 0-5 years old at the time of diagnosis.

The area of diagnosis that stood out was neurological pathology, with a total of 13 patients (52%), which is in agreement with the literature in terms of the description of neurological and oncological pathologies as the main causes of mortality in this context.[3,13-17] In the present study, only a small number of patients (n = 3) had an oncological diagnosis, which is justified by the fact that our hospital is not the reference center for the treatment of this type of pathology.

Most of the patients followed by our team were part of palliative needs groups III, which concerns progressive diseases without a curative therapeutic option, and IV, which refers to non-progressive irreversible diseases that lead to severe disability and eventually premature death. It should be mentioned that these groups are also associated with longer survival. This multidisciplinary team is part of a specialized unit integrated into a tertiary hospital, which benefits from organized and structured care support; therefore, the main reasons for referral were integration in the hospital and community care and symptomatic control.

Most of the children in this study were part of a family with a nuclear structure and mothers stood out as the main caregivers. Most of these patients had an advance care plan with guidelines for the optimization of comfort care, and even though every one of the parents became aware of it, only a small number was shared with them, as desired. As previously described, the advance care plan can include resuscitation and action plans in the face of clinical deterioration. This is because it is of great importance to both standardize the provided health care and help parents feel more prepared for the end of life of their children with a greater sense of control of the situation as they have been integrated into the decision-making process.

A significant number of patients (72%) were referred to the national long-term care network, which provides health care and social support. There are several typologies, such as convalescence units, medium-term and rehabilitation units, long-term and maintenance units, and home-based continuous care teams, the latter being the most frequently involved in the provision of care to the children followed by our team. The home-based continuous care teams, specifically, provide support in the community/home in conjunction with the PPCIHST through the mobile home support unit. This support includes medical and nursing care, food, hygiene, and education of caregivers (family and school) to help them autonomously care for these children.[18]

There was an equitable distribution in terms of age at the time of death date. A significant portion of the patients in this study died less than six months after referral to the team (56%), with a median value of six months (180 days) which seems to demonstrate a late referral, reinforcing the need for ongoing training of health professionals in this area. A study performed in Portugal assessed the knowledge of healthcare professionals about pediatric palliative care at a hospital institution. Results of the aforementioned study indicated that despite good knowledge of basic concepts, there were some barriers against referring the children, including the reluctance of parents to accept the referral, the discomfort of professionals regarding the discussion of this issue, and the association of this type of care to the end of life of these children.[19]

Our team has only been officially active for about four years (since 2018); therefore, it is a short period of time to provide conclusions on this matter, but it will be interesting to make a comparison with this initial period in the future. There are few studies in which the period between referral to pediatric palliative care and death is mentioned, and their median value is 50-134 days,[20-22] which is lower than the results of the present study.

The most common place of death was the hospital, followed by home with a percentage of 28%. The rate of death at home seems to be higher in the present research, compared to previous studies performed in Portugal. In the United Kingdom, there has been a growing trend of home death (21% in 2010), mainly in children with cancer, as it has been considered that this could mean a greater palliative care follow-up of these children.[3] In a study performed in eleven European and non-European countries in 2008, the home death rate in Spain (14.7%) was similar to that of the present research, while those of other countries, such as Belgium and Sweden, were significantly higher (42.1% and 34.8%, respectively).[23] Moreover, findings of a study carried out in Germany revealed that most deaths followed by this center occurred at home (84%) and that 96% of all deaths occurred in the place selected by the families.[17]

In the present study, 17 out of the 25 patients who died selected the place of death; moreover, six (35%) out of these 17 patients died at home. This means that six out of the seven deaths that occurred at home (86%) were the choice of the patients and their families. Selection of the place of death has been consistently considered as an indicator of the quality of palliative care for both adults and children, with the goal that death occurs more frequently at home in some countries.[24] It is also accepted that the preference of patients and families must always be taken into account, and they should be empowered to make it happen.[25]

A study also reported that planning the place of death is associated with a higher number of deaths at home, fewer hospital admissions, greater preparation of parents for the end of life of their children, and greater satisfaction / less regret with their place of death.[26] In a study published in 2020, several factors that may explain the differences between places of death in different countries were suggested, including characteristics of healthcare systems, cultural factors, and factors inherent to families and children.[27]

The collected data about the carried-out interventions demonstrate the availability and commitment of our team in monitoring these children and their families. It should be noted that this availability is offered continuously for 24 hours per day and seven days a week, using all the resources available.

Intervention in mourning, either in its preparatory form or after death, is a very important cornerstone at a very delicate moment that no one should go through, which is the death of a child. This intervention will provide skills to help deal with the loss and assist in the acceptance process. It should also be noted that the team accompanies the family all the way from the beginning of the follow-up to the grieving phase, as this process truly is teamwork with the family.

Concluding, a significant number of the patients had a neurological condition, as in previous studies. Moreover, a significant number of patients died in less than six months after the referral, which may demonstrate that the referral is occurring late, underlining the importance of creating specialized teams at the national level and training health professionals for this area of work. The main place of death remains the hospital, but an increasing trend of deaths at home appears to be taking place, possibly driven by follow-up in pediatric palliative care.

Author Contribuitions

MJP participated in the study conception or design. CS and MJP participated in acquisition of data. DP, CS, EF and MJP participated in the analysis or interpretation of data. DP, FS and IT participated in the drafting of the manuscript. CS, EF, FS, IT and MJP participated in the critical revision of the manuscript. All authors approved the final manuscript and are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Conflicts of Interest

The authors declare that there were no conflicts of interest in conducting this study.

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Protection of human and animal subjects

The authors declare that the procedures followed were in accordance with the regulations of the relevant clinical research ethics committee and with those of the Code of Ethics of the World Medical Association (Declaration of Helsinki 2013).

Provenance and peer review

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Confidentiality of data

The authors declare that they have followed the protocols of their work center on the publication of patient data.

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Mortalidade nos Cuidados Paliativos Pediátricos de um Centro Terciário

Introdução: As doenças crónicas complexas foram responsáveis por cerca de um terço do total de mortes pediátricas em Portugal nos últimos anos. A referenciação precoce e a realização de um plano antecipado de cuidados são estratégias que resultam numa maior preparação por parte das famílias para lidarem com o percurso da doença destas crianças. Este estudo teve por objetivo caracterizar dados da mortalidade dos doentes seguidos pela equipa intra-hospitalar de suporte em cuidados paliativos pediátricos de um centro terciário entre 2018 e junho de 2021.

Métodos: Estudo retrospetivo com análise dos processos clínicos dos doentes e de dados demográficos, grupos nosológicos, referenciação, expectativa e local de morte, bem como intervenções realizadas pela equipa.

Resultados: Foram acompanhadas pela equipa intra-hospitalar de suporte em cuidados paliativos pediátricos 64 crianças, das quais 25 faleceram (39%). Mais de metade destas crianças apresentava patologia do foro neurológico, tendo esta sido a área diagnóstica mais frequente. Catorze crianças (56%) faleceram menos de seis meses após referenciação à equipa. A maioria destas faleceram durante internamento hospitalar (56%), com 28% dos óbitos decorridos no domicílio.

Conclusão: Os dados sugerem uma referenciação tardia a cuidados paliativos pediátricos, razão pela qual é da maior importância investir na criação de equipas especializadas a nível nacional e formação dos profissionais de saúde nesta área. O principal local de morte foi o hospital, tal como em estudos prévios, embora com uma aparente tendência crescente de mortes no domicílio.

Palavras-Chave: Causas de Morte; Cuidados Paliativos/tendências; Criança; Doença Crónica/mortalidade; Lactente; Mortalidade Hospitalar; Planeamento Antecipado de Cuidados; Portugal; Pré-Escolar; Serviços de Saúde da Criança/tendências