





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Do patients with Duchenne muscular dystrophy receive the palliative care approach?

Abstract

Background: Palliative care (PC) is indicated for Duchenne muscular dystrophy (DMD), however, access to this approach is difficult.

Purpose: To verify whether patients with Duchenne muscular dystrophy (DMD) received the PC approach and evaluate the perceptions of health professionals about PC.

Methods: General information about the patient, interventions used to treat them, and PC approach were collected from the medical records. Health professionals completed a questionnaire designed to assess their knowledge about PC concepts. Data were analyzed descriptively.

Results: Twenty-five cases were analyzed. Patients received the multidisciplinary approach (84%) and 12% PC approach. Among the 58 professionals interviewed, 50% were unaware of PC assessment instruments, and 34.5% answered “no” or “I do not know” to the statement “Patients with DMD should receive PC since diagnosis”.

Conclusions: The isolated implementation of strategies aimed at improving the quality of life for DMD patients does not constitute an effective inclusion of PC in clinical practice. To effectively incorporate the PC approach in clinical practice, healthcare professionals must be sufficiently trained.

Palliat Med Pract

Keywords: pediatric palliative care, Duchenne muscular dystrophy, death, end-of-life care

Introduction

In pediatrics, an estimated 21.6 million children require access to palliative care (PC), including children diagnosed with Duchenne muscular dystrophy (DMD) [1]. The symptoms begin in early childhood and with the progression of weakness, patients lose

the ability to walk around age 9 years [2] and actual life expectancy is 28 years old [3]. The treatment in health care is aimed at increasing life expectancy and improving quality of life [4–6]. In 2014, the life expectancy of these patients was 20 years; thus, the increased survival of children with neuromuscular diseases makes using PC indispensable [7]. The purposes of DMD treatment

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are closely related to the principles of PC, as prioritized comfort and quality of life [8].

The PC approach entails a multi-professional therapeutic plan based on an early diagnosis [9]. To have a correct and early diagnosis of DMD, it is necessary to refer the patient to health units specialized in neuromuscular diseases [4]. Although the PC approach for patients with DMD has been recommended for many years, studies on such recommendations did not establish procedures or strategies designed to make the approach more grounded and practical [10–12]. Moreover, few studies have evaluated access by patients with DMD to PC and aspects related to the end of life for those with this patient profile [9, 13].

Access to PCs is complicated by barriers such as lack of resources, insufficient knowledge about existing services, and a shortage of adequately trained health professionals [14]. The ignorance of health professionals on this topic is one of the causes of the underutilization of PC services. As early as 1993, Hilton et al. [12] reviewed issues related to end-of-life care for patients with DMD and highlighted the need for changes in the practice of medicine. In 2017, Abbott et al. [13] stressed the need to expand the PC approach for patients with DMD and to insert PC into clinical practice, which can be achieved through continuing education strategies in healthcare services [15].

Considering the potential benefits of PC for patients with DMD, the following question is raised: Do professionals who care for patients with DMD know of PC? Do they recognize that this patient profile benefits from PC? Do these patients receive the PC approach during the disease? Answering these questions may contribute to the generation of propositions for improvements in treatment and work processes in health services. In this study, it was hypothesized that patients with DMD do not receive the PC approach during disease progression as a consequence of health professionals' lack of knowledge about the subject.

Considering that the diagnosis of DMD depends on a specialized service, the present study aimed to identify and report the conditions of death of patients with DMD who were followed in a tertiary hospital over 10 years and to verify whether they received a PC approach during the disease. Another aim of the study was to evaluate the knowledge about PC possessed by professionals at this tertiary hospital.

Material and methods

Sample

Analysis of deaths

A search was conducted of death cases between 2010 and 2020 in the database of the Physiotherapy

in Infantile Myopathies Outpatient Clinic and Neuromuscular Diseases Outpatient Clinic of Hospital das Clínicas da Faculdade de Medicina de Ribeirão Preto da Universidade de São Paulo (HCFMRP-USP).

Initially, patients whose death was registered in this database were identified. A search was conducted in the hospital's electronic medical records for the remaining patients who had no death records in the database. Subsequently, the responsible person was contacted by phone about those patients with no record of death and who had not returned to the hospital for more than 12 months. Ultimately, the civil registry office was consulted to verify the deaths.

The inclusion criterion was confirmed diagnosis of DMD and death. The exclusion criteria were: live patients (in follow-up), the inability to collect information about death and interventions due to the absence of this information in the medical record as well as no possibility of phone contact with family members of the decedents.

Analysis of the knowledge of the health professionals

A convenience sample of health professionals working at the HCFMRP-USP was evaluated. All professionals of this institution were invited to participate in the research via a questionnaire sent to them using the institution's e-mail. The questionnaire was available for one month. The inclusion criteria were as follows: completion of a graduate course (nursing, physiotherapy, speech therapy, medicine, nutrition, psychology, social work, or occupational therapy), prior experience treating patients with DMD, and providing consent to participate in the research by signing the informed consent form. The exclusion criteria were working as a technician or assistant nurse, working in administrative areas, or being in high school or enrolled in technical education.

Data collection

Analysis of deaths

The following data were collected from the medical records:

- general information: sex, age at diagnosis, age at which wheelchairs were used, precedence city;
- invasive interventions during the disease: cardiopulmonary resuscitation, orotracheal intubation, tracheostomy, gastrostomy, among others;
- pharmacological (regular corticoid use) and non-pharmacological treatments (non-invasive ventilation and a multi-professional approach);
- age, place, and clinical condition of death;
- whether a PC approach had been employed: attendance by the PC outpatient clinic, a record of

Table 1. Content analyses steps in the responses of health professionals

Step	Step description	Criteria used
Pre-analyses	Select document	Participants' response to the question "Briefly define what palliative care is and what is your perception of rehabilitation in this area"
	Define aims	To verify the knowledge of the participants concerning the concepts of PC
	Define hypotheses	Participants have general knowledge of the benefits of PC; however, with lack knowledge of specific concepts of this form of care
Codification	Registration unit	Keywords: quality of life, comfort, dignity, symptom relief, terminality, cure, end of life, death
	Context unit	The phrase in which the keyword is inserted
	Enumeration	Frequency of the keyword
Categorization	Grouping	<ul style="list-style-type: none"> • Entirely in agreement with the principles of PC: quality of life, care, symptom relief, dignity, patient-centered care • Partially in agreement with the principles of PC: quality of life and symptom relief, but focused on situations of terminality/chronicity • Not in agreement with the principles of PC: cure, terminality, disease-centered care

PC — palliative care

the term 'PC' appearing in the notes, and a record of discussion and definition of therapeutic goals, together with caregivers, that prioritized comfort and quality of life.

The data from the medical records were collected by two researchers who were previously trained in double-checking. For all deaths, an attempt was made to contact family members of the patients by phone to confirm the accuracy of the information contained in the medical chart and to collect unrecorded information.

Analysis of the knowledge of the health professionals

Data collection was performed, only once, using an online questionnaire (Google Forms; in multiple-choice format) prepared by the researchers of the present study, containing: graduation and area of expertise, concepts of PC, and a discursive question, "Briefly define what palliative care is and your perceptions about rehabilitation in this area".

Data analysis

Data were transcribed and stored in electronic spreadsheets, after which they were descriptively analyzed.

Analysis of deaths

For quantitative variables means and standard deviations were calculated. The information about treatment (pharmacological treatment, non-pharmacological treatment, PC approach, and invasive measures) were categorized as the occurrence or absence of these interventions and the percentage of occurrence.

Analysis of the knowledge of the health professionals

The answers to the discursive questions ("Briefly define what palliative care is and your perceptions about rehabilitation in this area") were analyzed using the content analysis method (Table 1) [16], analysis on the textual corpus, adopting basic lexicography (calculation of word frequency displayed in the word cloud) and similarity analysis (probabilistic network represented by a graph structure composed of relationships between words and their predicates) [17].

In this study, the analyses were performed considering a fixed significance level of 5% and with the computational support of the R program (version 4.0).

Results

Analysis of deaths

Sample characterization

Initially, in the outpatient clinic database, 12 deaths of patients with DMD (masculine sex) had been identified; in the steps of reviewing the medical records, telephone contact with the family, and active search in the registry office, the following were identified, respectively: 5, 5 and 4 deaths, totaling 26 deaths between the years 2010 and 2020 (Figure 1). However, one patient was excluded due to the absence of information in the medical records and the refusal of the family member to provide information by phone. Thus, the results refer to the analysis of 25 deaths (Table 2).

The age at diagnosis ranged from 4 to 10 years (mean 7.2 years, SD = 1.6) (Table 2). Of the patients, 44% were residents of cities that comprise the Health Regional District served by the HCFMRP-USP.

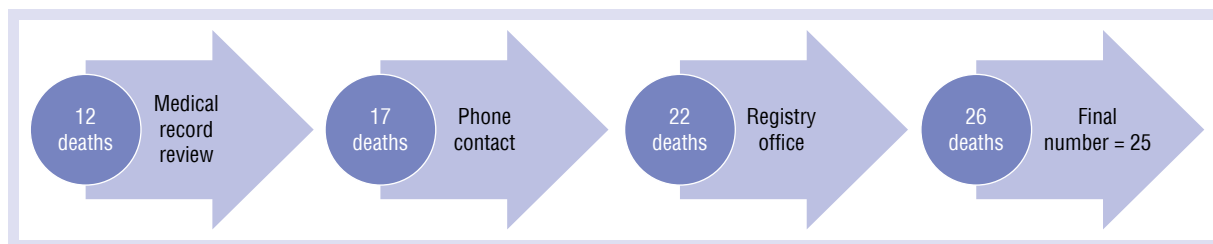


Figure 1. Flowchart for identification of deaths and selection of medical records; n — patient's number; + — more; m — months

Interventions were received during the disease course

The three main interventions were a multi-professional approach (84.0%), a pharmacological treatment (72.0%), and invasive measures (36.0%) (Figure 2).

The invasive measures performed were cardiopulmonary resuscitation (35%), orotracheal intubation (35%), gastrostomy (13%), and tracheostomy (17%). Notably, among all patients of cardiopulmonary resuscitation and orotracheal intubation, 62.5% occurred during the hospitalization in which death occurred.

Regarding ventilatory support (received by 36.0% of the sample during the disease), the mean age at the beginning of device use was 17.2 years (SD = 1.9 years), and a mask was the most common interface (77.8%).

Information about deaths and palliative care

Considering all samples (n = 25), the mean age at death was 20.1 (SD = 5.3) years, with the hospital unit being the most frequent location of death. Three deaths occurred at home, one of which was chosen by the family of the decedent.

The family report revealed that 12% of the patients (patient numbers 6, 14, and 17 in Table 2) received the PC approach during the clinical aggravation in which the death occurred. These three patients, two of whom died in the hospital unit while one died at home, underwent invasive measures.

Analysis of the knowledge of the health professionals

Sample characterization

The final study sample included 58 professionals. The average age of the participants was 33.3 (8.6) years, 81.3% of whom were female and 18.7% male. Regarding education, nurses (10.3%), physical therapists (50.0%), physicians (29.3%), and others (10.3%: social workers, speech therapists, pharmacists, and nutritionists) participated. Of the participants, 8.6% had less than one year of experience, while 39.7% had between 1 and 5 years of experience, and 51.7% had more than five years of experience.

All participants reported having already heard the term 'palliative care', with 24% hearing about it during professional practice, 69% learning about it during undergraduate education, and 7% in other places.

Knowledge about palliative care

It was observed that the concepts of total symptom, total pain, and conspiracy of silence were unknown by 51.3%, 43.1%, and 77.5% of the sample, respectively (Table 3).

Of the 58 participants, 50% did not know the acronyms SPIKES (bad news communication protocol), PPS (Palliative Performance Scale), PPI (Palliative Prognostic Index), and ESAS (Edmonton Symptom Assessment System), and 34.5% answered "no" or "I do not know" to the statement "Patients with Duchenne dystrophy should receive PC since diagnoses".

It was observed that the keywords that appeared more frequently were quality of life (65.5%), comfort (13.8%), and symptom relief (10.3%). There was no mention of the term 'death' (Table 4).

In the categorization step, the grouping factor agreed with the principles of PC (totally agree, partially agree, disagree). Of the answers, 91.2% were totally in agreement and 8.8% were partially in agreement. No response indicated disagreement.

To better understand the categorization results, excerpts of the answers categorized as partially in agreement are transcribed below, with comments considered inconsistent with the concepts and principles of PC highlighted (in bold):

- "Palliative care is caring to improve the quality of life of the patient and family members during a progressive and **terminal** disease process".
- "It consists of active and/or total care of the patient in **whom the disease evolves and does not respond to treatment**, focusing on pain relief as well as the other physical symptoms".
- "Palliative care is an approach that seeks to offer the quality of life — that is, »less suffering« — to the **terminally** ill patient and their family members".
- "Palliative care is all of the procedures performed to improve and maintain the quality of life of

Table 2. Sample characterization of 25 individuals who died

Patient (P)	Age at diagnosis (years)	Age WD (years)	Corticosteroid use	Treatment non-pharmacological						Ventilatory support			Invasive procedures?	Palliative care	Death	
				Multiprofessional approach			SS	Use?	Age (years)	Interface	Age (years)	Place				
				PT	ST	N									Psy	OT
P1	6	10	■							■	18	Mask			*	*
P2	7	8	■	■									■		18	Home
P3	4	11	■	■						■	15	Mask			28	*
P4	7	10	■	■						■	16	Mask			18	*
P5	9	9	■							■	16	TQT	■		26	*
P6	7	10	■	■						■			■		17	Hospital
P7	10	11	■	■						■			■		15	Hospital
P8	7	7	■	■						■					11	*
P9	5	11	■	■						■			■		21	Hospital
P10	12	11	■												NI	Hospital
P11	7	10	■	■						■	18	Mask			19	*
P12	7	14	■	■						■					32	Hospital
P13	5	9	■	■						■	18	Mask			*	*
P14	6	9	■	■						■	17	Mask	■		19	Hospital
P15	8	13	■	■						■					20	*
P16	5	13	■	■						■					19	*
P17	4	11	■	■						■	21	TQT	■		27	Home
P18	11	10	■	■											18	*
P19	5	8	■	■						■	16	Mask	■		17	Home**
P20	10	12	■	■						■					*	*
P21	8	13	■	■						■			■		17	Hospital
P22	11	9	■	■						■					19	*
P23	3	9	■	■						■					16	*
P24	10	9	■	■						■					18	*
P25	6	7	■	■						■					15	*
Y [%]	-	-	72%	84%	42%	36%	28%	48%	40%	36%			36%	12%	-	-
Mean (SD)	7.2 (1.6)	10.1 (1.9)									17.2 (1.9)				20.1 (5.3)	-

* — no information (no medical record); ** — family's decision; N — nutrition; OT — occupational therapy; PT — physical therapy; Psy — psychology; SD — standard deviation; SS — social service; ST — speech therapy; TQT — tracheostomy; WD — wheelchair dependent (age in which the patient became WD); Y [%] — percentage of "yes" answers

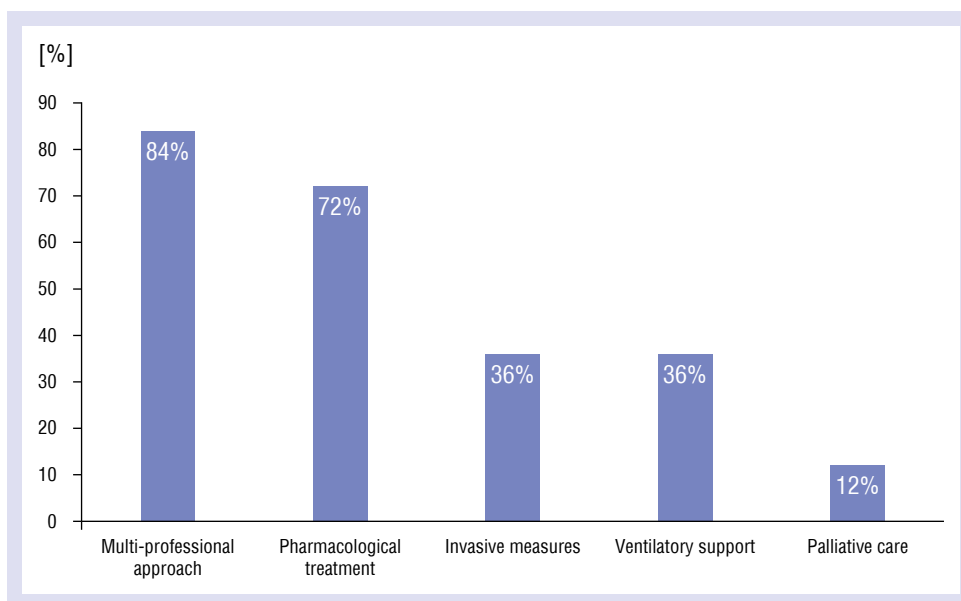


Figure 2. Interventions received during the disease course of DMD among 25 individuals who died

Table 3. Questions and percentage of answers about concepts and palliative care principles

Questions*	Yes	No	I don't know
Is your profession related to PC?	98.3	1.7	0.0
When a patient is in PC, it means that there is nothing more to be done	5.2	94.8	0.0
In PC, there is the concept of "total symptom"	46.6	8.6	44.8
Total pain is defined as an unpleasant sensory experience that simultaneously affects several regions of the body	43.1	27.6	29.3
Do you know or have you heard the expression "conspiracy of silence"?	22.4	67.2	10.3
Do you know any of the following acronyms? — SPIKES, PPS, PPI, ESAS	50.0	43.1	6.9
Duchenne dystrophy patients should receive CP from the time of diagnosis	65.5	15.5	19.0
The palliative approach should be performed preferably during hospitalization	22.4	67.2	10.3
Rehabilitation centers are places to talk about PC	84.5	3.4	12.1
When a patient is in PC, it means that he has no more chance to improve functionality/ motor skills	3.4	93.1	3.4
Rehabilitation allows for improving the quality of life of a patient with PC	100	0.0	0.0

* Answers are expressed as a percentage (%) concerning the total responses; ESAS — Edmonton Symptom Assessment System; PC — palliative care; PPI — Palliative Prognostic Index; PPS — palliative performance scale; SPIKES — bad news communication protocol

bedridden patients with chronic degenerative and/or progressive illnesses".

Through the analysis of the textual corpus, a cloud of words was obtained (Figure 3), one that represents the definition of PC for the evaluated group of health professionals. Notably, the most important word in this cloud is "patient" — the word that received the most citations. The second and third most cited words were "life" and "quality", respectively.

In the similarity graph (Figure 4), the interconnections between words and constructs — according to

the groupings — show, in effect, that patients are central to PC, as directly indicated by the words themselves: symptom, quality, life, and care.

Discussion

Although healthcare professionals generally view PC as beneficial, the PC approach has been employed more restrictedly in pediatric patients [18]. The results of this study confirmed the hypotheses that patients with DMD had limited access to PC and that concepts specific to PC are not widely known by the professionals

develop training strategies that target specific concepts of this form of care for patients with DMD. Although all the professionals included in the study possessed some knowledge of the term 'palliative care' and more than half (65.5%) associated PC with the term 'quality of life', some still associated PC with terminally, and 50% did not know about important concepts such as SPIKES (bad news communication protocol), the conspiracy of silence or evaluation scales in PC (ESAS, PPS, PPI). Additionally, 34.5% of the participants did not know whether their DMD patients had indications for PC since diagnosis. These findings corroborate claims in the literature that lack of knowledge on the part of health professionals is one of the main barriers to accessing PC [14].

The content and similarity analysis on answers to questions concerning concepts and principles of PC indicated that health professionals should be better trained on these topics. On the one hand, the discursive answers were not in disagreement with the principles of PC, and the professionals understood that, in PC, the patient is the central focus of every approach. However, on the other hand, more than half of the sample did not know about concepts such as, for example, total symptom, the siege of silence, or the acronyms ESAS, PPS, and PPI (palliative care assessment scales). Other authors have reported that health professionals have superficial knowledge about PC [22, 23]. The professionals who participated in the present study understood the term 'palliative care' but were unaware of important strategies and tools for implementing this form of care in actual clinical practice.

The limitations of this study were: the low response rate of the survey; the current model of electronic registration was identified concerning the analysis of deaths: succinct registration of care, outdated phone contact information in hospital records, and the absence of information about symptoms occurring at the end of life. As a differential in health, it is worth highlighting the importance of qualitative studies in the field of PC. When dealing with such a broad — yet integral — form of care, it is necessary to give voice to the research subjects so that it is possible to capture intimate and varied details for which numbers alone cannot account. Thus, it is recommended that more qualitative research be conducted to investigate the management of symptoms in patients with DMD at the end of their life.

Conclusions

Only 12% of sampled patients whose disease course had progressed to death had received the PC approach. The isolated implementation of strategies

aimed at providing comfort and quality of life for patients with DMD does not constitute an effective inclusion of PC in clinical practice. As such, it is recommended that training strategies be developed for implementation among care teams specific to this patient profile, starting with multi-professional teams in the hospital, as these are the main sites of death for patients with DMD. It is necessary to assess the degree to which such training results in the modification of interventions and end-of-life records for patients with DMD in the medium- and long term.

Article information and declarations

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Data availability statement

Not applicable.

Ethics statement

The study was approved by the ethical and research committee of HCFMRP under opinion no. 98189118.3.0000.5440.

Author contributions

Conceptualization, methodology, investigation, writing: original draft preparation, writing: review and editing — MA de SL; formal analysis, methodology — EA da SL; investigation — SCPV; resources — CF da RS; conceptualization, funding acquisition, project administration, writing: review and editing, supervision, validation — ACM-S.

Conflict of interest

The authors declare no conflict of interest.

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Supplementary material

None.

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