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ORIGINAL ARTICLE

Therapeutic effort adequacy directives. Experience of a Pediatric Palliative Care Unit

Directivas de adecuación del esfuerzo terapéutico. Experiencia de una Unidad de Cuidados Paliativos Pediátricos

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What do we know about the subject matter of this study?

In the care of children with life-threatening diseases, scientific and technological advances present new clinical and ethical challenges. "Directives for the adequacy of treatment effort" help define, at each stage, the measures appropriate to the patient's clinical condition.

What does this study contribute to what is already known?

Almost one-fifth of the children cared for by the reference Pediatric Palliative Care Unit in Uruguay had "Directives for the adequacy of treatment effort" in place. In most cases, these directives were defined by the interdisciplinary team together with the child's parents or caregivers and recorded in the patient's clinical history. Among the children who had such directives and passed away, in most cases, these recommendations were followed.

Abstract

Limitation of medical treatment (LOMT) directives are a relevant clinical-ethical procedure in the care of children with life-threatening conditions. **Objective:** To describe the percentage and characteristics of patients with LOMT records, including recommendations, time to implementation, and adherence. **Patients and Method**: Retrospective study between 2009 and 2024, in children cared for by the Pediatric Palliative Care Unit of the *Centro Hospitalario Pereira Rossell* in Uruguay (UCPP-CHPR). The variables evaluated were age, pathology, participants in decision-making, record, measures "to be performed" and "not to be performed", time between UCPP-CHPR referral/ LOMT decision and between LOMT/ death, place of death, and adherence to the LOMT directives. **Results**: LOMT were recorded in 18.2% (244/1341) of patients; the median age was 4.8 years and 66% had severe neurological impairment. Healthcare teams and caregivers participated in the decision-making process in 88% of cases. The record was performed in a specific form in 88.5% of the cases. The LOMT directives included "*to be performed*": analgesia and comfort care (100%), admission to the general

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pediatric ward (96%); and "*not to be performed*": cardiopulmonary resuscitation (96%), admission to intensive care (98%), and mechanical ventilation support (98%). 4 patients underwent compassionate extubating. The median time between UCPP-CHPR/ LOMT was 6 months. A total of 77.4% (189/244) of the patients died, 70% of them while admitted. The median time between LOMT/ death was 3 months. The adherence rate to LOMT directives was 98%. **Conclusions:** Almost one-fifth of the children cared for by the UCPP-CHPR had LOMT directives. In most cases, healthcare professionals and caregivers participated in the decision-making process, and the directives were recorded in a specific form in the clinical history. In almost all deceased children, the LOMT directives were respected.

Introduction

In all pediatric health care settings, a significant and probably growing number of children[a] with complex chronic health conditions and life-threatening diseases (LTD), often technology-dependent, are cared for and, according to the definitions of the World Health Organization (WHO) and the American Academy of Pediatrics, among others, benefit from receiving Pediatric Palliative Care (PPC) from the time of diagnosis[1,2]. Throughout the life of children, health professionals, along with parents and/or other caregivers, face multiple questions regarding the relevance and/or proportionality of certain measures, and whether these are truly "*in the child's best interest*". Therefore, in the context of PPC, together with the other components, Advance Care Planning (ACP) and, sometimes, Treatment Limitation Directives (TLD) are essential clinical and ethical procedures that guide and support the continuity of care, guaranteeing that this is truly focused on the child's best interest[3,4].

ACP consists of conversations between the health professionals caring for the child and between them and the child (if possible) and/or their family to reach a shared understanding of the child's clinical situation. Also, getting to know and understand their values, goals, and preferences regarding current and future medical care. These conversations take place over time, in a series of meetings, covering a wide range of topics, including the "*goals of care*" at any given time[3,4].

Sometimes, the ACP may include the treatment limitations (TL), which are medical indications aimed at adjusting treatments to the patient's clinical progression[4]. These are well-considered decisions of the professionals on the non-implementation (non-initiation or suspension) of therapeutic, diagnostic, and/or monitoring measures, when they anticipate that these do not entail a significant benefit for the patient. Simultaneously, it implies the reinforcement of all those measures that may be necessary, proportionate, and according to the *goals of care*, particularly those needed to promote comfort and quality of life[3,4].

The ACP and DATE are supported by a robust ethical foundation[7,8]. In Uruguay, as in other countries, they also rely on an important legal framework of reference[8-13]. In addition, ACP and DATE are currently considered essential components of the quality of care for people with LTD, mentioned in the main international protocols of quality standards in PPC[14-17].

In Uruguay, since 2008, at the *Centro Hospitalario Pereira Rossell* (CHPR), a national pediatric public reference hospital, the Pediatric Palliative Care Unit of the CHPR (PPCU-CHPR) has created and implemented a protocol for analysis and decision making for the definition of DATE[18]. The DATE form is prepared specifically for each patient and contains systematic information such as: patient's personal data; participants in the ACP process from both the team and the family; brief summary of the child's clinical situation at the time of registration; goals of care; recommendations for measures "to be performed" and "not to be performed" in case of clinical deterioration; and signature of the health professionals involved in the process. To date, the institution has not yet achieved its complete and visible inclusion in the electronic medical record.

A previous communication reported that 11.8% of the patients seen at the PPCU-CHPR had DATE in their medical records[19]. A survey of physicians and nurses at the same hospital showed that 75% of the respondents had cared for patients with DATE and that most of them considered them useful or very useful[20]. The objective of this research is to update clinical knowledge on the subject, 17 years after the beginning of the work of the PPCU-CHPR.

Patients and Method

Design

Descriptive, retrospective study from January 1, 2009, to December 31, 2024. All the children seen at the PPCU-CHPR with a history of DATE were included. A DATE record was considered valid whether it was

a Within the context of this document, whenever it says "children", it means boys, girls, and adolescents.

as a note in the progress section of the medical record or as a specific, individualized form printed on a green sheet.

The health conditions that made children eligible for PPC were classified according to the 2018 classification of "Together for Short Lives".

The information source included medical records and PPCU-CHPR records. A data collection form was created specifically for this study.

Variables to be evaluated

From the data of children seen at the PPCU-CHPR during the study period, the following were evaluated: i. The percentage and demographic and clinical characteristics of those with DATE records; ii. The measures that were indicated as "to be performed" and "not to be performed"; iii. The time elapsed between initiation of care at the PPCU-CHPR and completion of the DATE record, and between completion of the DATE record and the death of the child; and iv. The degree to which DATE were respected in deceased children.

Variables recorded

a) Of the children: age (years, months, and days), sex, origin department, condition that made them eligible for PPC, prosthesis and/or medical technology devices (type, number), main caregiver.
b) Of the ACP process: participants (family/caregiver, health team); record (progression sheet, specific form).
c) Recommended measures: "to be performed"; "not to be performed".

The time elapsed between inclusion of the child by the PPCU-CHPR and registration of DATE, and between registration of DATE and death (median of months or years) was evaluated. In deceased children, it was recorded where the death occurred (hospital: emergency/pediatric ward/intensive care) or at home, and the compliance or respect of the DATE by health professionals.

Data analysis

Discrete qualitative and quantitative variables (absolute and relative frequencies) and continuous quantitative (measures of central tendency and range) were evaluated. The JASP software was used.

Ethical aspects

This study was approved by the CHPR Pediatric Hospital management and the institution's Research Ethics Committee.

Results

During the period analyzed, the PPCU-CHPR cared for 1,341 children, of whom 407 (30%) died. Of the total number of children seen during the study period, 18.2% (244/1341) had a DATE record: 11.8% (73/618) performed from January 1, 2009, to December 31, 2015, and 23.6% (171/723) from January 1, 2016, to December 31, 2024 ($p < 0.005$).

The median age of the included patients with DATE was 4.8 years (range 1 month 12 days-18 years 11 months), 51% (124/244) were male, and 98.4% (240/244) were from Uruguay. Most of the children (66%) had severe chronic encephalopathy. Table 1 describes the total diseases that made the children eligible for PPC. 83% (202/244) of the children used at least one prosthesis or medical technology device; of these, 14% (28/202) had 3 or more devices which were nasogastric tube 45.5% (92/202), gastrostomy 36.1% (73/202), tracheostomy 30.1% (61/202), ventilatory support 18.3% (37/202), ventriculoperitoneal shunt 18% (36/202), central venous catheter 1.5% (3/202), low-flow nasal cannula oxygen 1% (1/202), and Kehr's T-tube 1% (1/202). In 50.4% (123/244) of the cases, the main caregiver was the mother; 25% (60) both parents; 13.5% (33) a foster care institution under the legal protection of the Uruguayan Children and Adolescents Institute [INAU (Spanish)]); 7.4% (18) grandparents; 3.3% (8) the father, and in 0.4% (1) of the cases was an uncle/aunt.

Regarding the ACP and decision-making process, in 88% (215/244) of the cases, the participants were the interdisciplinary team together with the main caregiver, and in 12% (29/244) was exclusively the professional team, who reported the decisions to the family (3) or to the INAU (26), as appropriate.

The DAET were recorded in a specific, individualized form and included in the patient's medical record in 88.5% (216/244) of cases, and as a progress note in 11.5% (28/244). Table 2 shows the recommended "*to be performed*" and "*not to be performed*" measures in case of possible clinical decompensation. Compassionate withdrawal of ventilatory support was performed in four children with end-stage severe chronic non-progressive encephalopathy: two in intensive care underwent palliative extubation, and two in the pediatric ward had ventilatory support withdrawn (1 via tracheostomy, 1 via noninvasive ventilation).

The median time elapsed between the start of care by the PPCU-CHPR and the registration of DATE was 6 months (range 0 days-4 years 3 months).

Of the children with DATE, 77.4% (189/244) died; 70% (132/189) of them at the hospital and 30% (57/189) at home. Of those who died in the hospital, 81% (107/132) died in the pediatric ward, 12%

(16/132) in the ICU, and 7% (9/132) in the emergency room. The median time elapsed between DATE registration and death were 3 months (range 0-9 years 7 months).

Among the deceased children, the recommendations included in the DATE were followed in 98% (185/189) of cases. The reasons for non-compliance were a lack of awareness of the DATE (3/4) and disagreement among those caring for the child (1/4).

Discussion

Multiple authors highlight the benefits of ACP in the care of children with LTD, including better end-of-life preparation, reduced perceived suffering, and better experience during this stage[3,22,23]. Children and parents value ACP because it empowers them to make better decisions and prepare and facilitate coping. Health professionals also value having a record that shows the analysis and planning done by those who know the patient and family best and information about the child's clinical situation, "goals of care", and recommendations for action in case of clinical decompensation[20,24]. The reflection of the ACP conversations between the healthcare team, the patient, and the family must be clearly recorded in the medical records of all patients with life-threatening and/or life-limiting conditions, in a timely manner, at different points along the disease trajectory, and not only during the end-of-life stage[1,3].

In Uruguay, in 2008, the first national publication

Table 1. Diseases or health conditions of patients assisted by the Pediatric Palliative Care Unit (PPCU-CHPR) with a record of DATE between 2009–2024 (N: 244)

Diseases or health conditions according to *Together for Short Lives*	Absolute frequency	Relative frequency
Group I: Diseases requiring curative or intensive treatment to prolong life, which may fail	31	13
Advanced or progressive neoplastic diseases with poor prognosis	18	
Severe congenital or acquired heart disease	13	
Group II: Diseases requiring long-term treatments to improve and maintain quality of life	24	10
Severe gastrointestinal diseases or malformations	8	
Muscular dystrophy or other neuromuscular diseases	6	
Renal failure when dialysis or transplant is not indicated	3	
Chronic or severe respiratory failure	3	
Chronic cirrhotic liver disease with no possibility of transplantation	2	
Spondyloepiphyseal dysplasia. Severe thoracopathy	1	
Stiff skin syndrome	1	
Group III: Progressive diseases for which treatment is exclusively palliative	28	11
Genetic syndromes	14	
Progressive metabolic disorders	10	
Chromosomal abnormalities (13 and 18)	2	
Severe osteogenesis imperfecta	1	
Mucopolysaccharidoses	1	
Group IV: Severe chronic encephalopathy leading to vulnerability and complications that may cause premature death	161	66
Central nervous system malformation	33	
Perinatal hypoxic–ischemic syndrome	25	
Central nervous system infection	23	
Genetic cause	17	
Post-neonatal hypoxia (resuscitated cardiorespiratory arrest)	17	
Secondary to external injuries	15	
Unclear etiology	14	
Complications of extreme prematurity	12	
Multifactorial	5	

DATE: Directives for the Adequacy of Therapeutic Effort; PPCU-CHPR: Pediatric Palliative Care Unit, Centro Hospitalario Pereira Rossell.

Table 2. Recommended "to do" and "not to do" measures included in the DATE record in children assisted by the PPCU-CHPR (2009–2024) (N: 244)

Therapeutic measures	Absolute frequency	Relative frequency (%)
Indications "To do""		
Comfort measures and analgesia via enteral and parenteral routes	244	100
Hospital admission to general pediatric wards	234	96
Oxygen therapy by non-invasive methods	215	88
Indications "Not to do"		
Mechanical ventilatory support	239	98
Admission to intensive care	239	98
Attempt of cardiopulmonary resuscitation	234	96
New invasive procedures	224	92
Initiation of inotropic drugs	6	2.5
Initiation of dialysis	4	2
Blood product transfusion	3	1.2
Increase in ventilatory parameters	3	1.2
Non-invasive ventilatory support	2	1

DATE: Directives for the Adequacy of Therapeutic Effort; PPCU-CHPR: Pediatric Palliative Care Unit, Centro Hospitalario Pereira Rossell

on limitation of life support measures in children in intensive care showed that 15% of deaths occurred as a consequence of limitation or withdrawal of life support[25]. Since the same year, the PPCU-CHPR has developed and implemented a process of ACP and DATE based on international protocols and recommendations and has initiated the visibility and placement of the subject in the clinical, educational, research, and dissemination agenda[18-20,26-28].

This study, which followed a similar methodology and included the period reported in 2017 by the same service, identified a significant increase in the number of patients with DATE. This difference is possibly multifactorial, caused by the learning curve of the team over the years, among others, as was also pointed out by Martin et al.[29].

The difference in the number of ATE procedures of Uruguayan PPC teams, with differences in professional training and experience, may support this hypothesis[30], but also the clinical progression of the patients cared for, mostly children with severe neurological disease and use of multiple prostheses and devices. Some of them survive for long periods; however, over time, they develop a progressive deterioration in their overall health condition. This determines that measures which, for long but variable periods, had been beneficial and proportionate, are no longer so as the disease progresses and both its course and quality of life decline[31,32].

The learning curve of the professional team and major health conditions of the children included could also be the reasons, among others, why only a small number of children cared for by the PPCU-CHPR have DATE. This, along with other qualitative analyses, will be of interest to conduct in the future to complete the understanding of the impact of this clinical-ethical procedure on the lives of children and their families.

These results can serve as input for future reflections by health professionals regarding the best time to initiate ACP conversations. Ideally, these should start early, during moments of clinical stability, and act as the "*light*" guiding professionals' decisions. "*Not everything technically possible is ethically acceptable*."

Prostheses and medical technology devices should be implemented after an adequate clinical-ethical balance that reasonably demonstrates greater benefits than suffering or burden for the patient, and not as a way to solve a healthcare problem. The decision to implement a medical treatment that includes a life-support intervention should be made after answering the essential question: "*Does this treatment benefit the patient?*"[4]. Prostheses such as a tracheostomy or chronic ventilatory support devices may extend the patient's life, but they do not always determine an improvement in quality of life. On the contrary, sometimes these devices add a significant burden of discomfort, comorbidities, and suffering for the child and family.

It is important to emphasize that the non-application of an existing, well-known therapy, procedure, or medical act within the framework of a DATE process does not mean that the patient cannot access other, less complex therapies that may still provide some benefit at that time. This should be analyzed and reanalyzed periodically, evaluating whether the benefit persists or not, and considering the need to define new DATE, according to the progression.

In most cases, the ACP and decision-making process were carried out by the professional team together with the family, according to the shared decision-making strategy. This seems to show an increase in family participation with respect to previous national studies[19,25,26]. Although this study did not delve into the characteristics of the process, it should include discussions among all professionals involved in care in order to jointly analyze the trajectory of the disease, identify a turning point, and discuss the benefits and disadvantages of different possible courses of action[18] as well as conversations with the children if possible due to their clinical condition and maturity and with their families or guardians.

Although technical decisions are made by the professionals, in the context of palliative care, these are made considering the values, wishes, and preferences of the patients and their family, in order to provide the care that best suits each one[4,18].

In some cases, the definition of DATE was unilateral, mainly in children who, by court order, were under the care of INAU and who, in Uruguay, do not have a person fulfilling the role of guardian. According to the AAP: "*It may be ethically justifiable to carry out DATE without family agreement in exceptional circumstances of extreme treatment burden or suffering with no benefit to the patient, beyond merely postponing death*"[15].

It is often mentioned that in ACP, what matters most is the process and the exchange among the different parties, rather than the existence of a document; however, to ensure continuity of care according to the defined "*goals of care*", it is essential to record the outcome of such conversations[4]. "*The existence of high-quality and accessible ACP forms facilitates the communication of patients' wishes as they move through the different settings of the health care system*"[33].

There is no single form of ACP or DATE registration. Various PPC services do it differently: spontaneous records, semi-structured formats, to standardized forms to be completed with patient information[(33)]. In this study, it was found that most DATE records were kept in a specific, individualized paper form. The failure to include the DATE form in a visible way within the electronic medical record may represent a barrier to the child's care. In an emergency, parents may forget to bring the printed form, leaving the attending professionals, who do not know the child, without the necessary information to act, as happened in some cases. Berkowitz et al, in their evaluation of the quality of the ACP documentation, pointed to the "accessibility" of the form as a key quality criterion[(33)].

In addition to the written record, it is important to communicate the decisions made to primary care professionals and local emergency services, and to provide them with a copy of the form. If such a plan and the "*do not resuscitate*" decision are recorded in the ambulance service's medical record, it will be easier for them to avoid offering inappropriate resuscitation attempts in the event of an emergency[34,35].

Regarding the content of the DATE, it was found that the recommended measures "*to be performed*" always included "*comfort and pain relief measures*". This is consistent with the fact that ATE does not only mean limiting care but, in all cases, continuing or instituting all measures aimed at maintaining and/or improving the patient's quality of life. It was also found that almost all DATE included the suggestion of "*no attempt at CPR*" and, to a lesser extent, no use of MV or admission to intensive care. These are some of the measures mentioned by different authors as subject to limitation[15,23]. There were few records of limitations of measures, such as blood product transfusion was found, and none for chemotherapy. This is likely related to the small number of children with oncologic conditions who, for reasons external to the service, are not cared for by the PPCU-CHPR. The AAP and other authors include these measures among those that may be limited if the child's clinical condition and the defined "*goals of care*" warrant it[15,36].

In four children, the DATE included compassionate withdrawal of ventilatory support, which consists of removing the endotracheal tube and/or discontinuing MV, as well as other forms of critical care support. It is a clinical ATE procedure that should be considered when it is recognized that MV is no longer in the "*best interests of the child*". The decision for extubation and/or compassionate withdrawal of ventilatory support is one of the most difficult, both intellectually and emotionally, and often raises ethical and legal doubts among professionals and the public. However, the primary ethical and legal principle is that all treatment decisions must be made in the best interest of the child[14,21]. In Uruguay, the law states that "*Every patient has the right to respectful and dignified treatment*". This includes "*to die with dignity, understood within this concept as the right to die naturally, in peace, without pain, avoiding in all cases ... artificially prolonging the patient's life when there are no reasonable expectations of improvement (therapeutic futility)*"[9].

In this study, all the children who underwent compassionate withdrawal of ventilatory support were hospitalized in intensive care units or pediatric wards, as is most common. However, in recent years, the literature shows a growing trend for this process to also take place outside the hospital, bringing the child home or to a pediatric hospice as part of their end-of-life care plan[37]. This requires a PPC team capable of providing 24/7 out-of-hospital care year-round, which is not possible for the PPCU-CHPR or for most PPC teams in Uruguay or Latin America[30,35,38].

The percentage of children with DATE who died is significantly higher than the percentage of those who died in the total population of children cared for by the PPCU-CHPR, which shows that the former were clearly going through a different stage of the disease trajectory, mostly at the end of life. As in the previous communication, of the children who had DATE and died, the majority died in the hospital, in the pediatric ward and, to a lesser extent, in intensive care. Although dying at home has traditionally been pointed out as an indicator of quality end-of-life care, this is not necessarily the case, as it depends, among other factors, on the clinical nature of the outcome, peaceful or with distressing symptoms, and on the ability of the healthcare system to meet the child's needs[39].

The lack of comprehensive PPC services, both in material and human resources, to care for the child at home 24/7 year-round, as exists in other countries, is a determining factor in whether to consider is possible to accompany a child's death at home[40,41]. Unfortunately, in Uruguay, it is also difficult to enter some areas for security reasons, particularly at night. These factors determine that, sometimes, at the end of life, it is necessary to hospitalize the child in the pediatric ward, providing the greatest possible comfort and flexibility in the routines to provide an equally humane and warm environment for the children and their families.

In the context of PPC, together with comprehensive symptom management, effective communication, and psycho-social and spiritual support, ACP and ATE represent important strategies to help improve the quality of life of children with TLD and their families. They promote patient care according to their life stage, wishes, and preferences, while also promoting more compassionate and equitable healthcare.

The results presented are expected to serve as inputs for the reflection and education of healthcare professionals and to help reduce the barriers that still remain in this regard[42,43]. "*ATE is a humanized medical action based on the ethics of care and the philosophy of PC, allowing for the incorporation of an approach centered on care, support, and accompaniment, shifting from the art of healing to the art of caring*"[4].

Within the limitations of the work, given its quantitative and retrospective nature, this study did not delve into other characteristics of the ACP process that could motivate further research using a prospective and qualitative or mixed methodology. The limited inclusion of children with cancer, due to external factors beyond the team's control, likely determines biases regarding the results found and leaves unexplored areas, particularly the direct inclusion of the voice of children and adolescents.

In conclusion, of the children cared for by the reference PPC unit in Uruguay, 18.2% had a record of DATE, the median age was 4.8 years, and most had a chronic non-progressive encephalopathy and used prostheses and/or medical technology devices. For most of them, the ACP process was carried out by the professional team together with the parents/caregivers, and the record was made in a specific, individualized form, included in the clinical history. Of the children with DATE who died, at the time of death, the recommendations were followed in almost all of them.

Ethical Responsibilities

Human Beings and animals protection: Disclosure the authors state that the procedures were followed according to the Declaration of Helsinki and the World Medical Association regarding human experimentation developed for the medical community.

Data confidentiality: The authors state that they have followed the protocols of their Center and Local regulations on the publication of patient data.

Rights to privacy and informed consent: This study was approved by the respective Research Ethics Committee. The authors have obtained the informed consent of the patients and/or subjects referred to in the article. This document is in the possession of the correspondence author.

Conflicts of Interest

Authors declare no conflict of interest regarding the present study.

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