

Prevalence of pain in the last 2 weeks of life in hospitalized pediatric patients

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Abstract

Introduction: Pain is a very common symptom in children who have a complex, chronic, life-threatening or life-limiting disease, generating a negative impact on the quality of life of the child and his or her family. There is very limited evidence regarding end-stage symptoms in pediatric patients receiving palliative care; Baumann et al. described in 2021 the presence of pain in 56% of their terminally ill patients. So far, there have been no studies in Latin America on the prevalence of pain in the last weeks of life in pediatric patients. **Objective:** The study aimed to determine the prevalence of pain in the past 2 weeks of life in children who died in the Hospital in the past 5 years. **Materials:** A retrospective, observational, and longitudinal study was carried out in which the records of patients over 1 month of age and under 18 years of age who died in hospital were included. **Results:** The records of 98 patients who died during their in-hospital stay were obtained, of which 52 reported the presence of pain in their past 2 weeks of life. Most of the patients were teenagers; oncological pathologies were the most frequent. In less than half of the patients, the use of a tool to assess the intensity of pain was reported, with the verbal numerical scale being the most used. Severe pain was reported in nearly half of the patients, and in a quarter of the children, its intensity was not described. About 71.2% of the children were managed with opioids (alone or in combination with other drugs). Only a third of the subjects were evaluated by the Algology service Pediatric. **Conclusions:** Timely identification and treatment of pain, especially in terminal phases, is essential to reduce the suffering and agony of these patients. To this end, its assessment by the Pediatric Algology service can favor comprehensive management and adequate control of the symptom.

Keywords: Pediatrics. Pain. Terminal phase.

Introduction

The International Association for the Study of Pain (IASP) in 2020 proposed a new definition of pain, considering that “it is an unpleasant sensory and emotional experience associated with or similar to that associated with actual or potential tissue damage.” It is experienced as the result of a set of physical, psychological, social, and spiritual factors¹⁻³.

It can be classified according to neurophysiological mechanisms into nociceptive and neuropathic pain. The first is that which is produced by activating nociceptors, which, in turn, depending on its origin, can be classified as somatic or visceral. Neuropathic pain is generated as a cause of an injury or disease of the somatosensory nervous system and is divided into central or peripheral³. It can also be classified according to its duration as acute (< 3 months) and chronic (more than 3 months)^{3,4}.

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Pain is a very common symptom in children of all ages, mainly for children who have a complex, chronic, life-threatening or life-limiting disease, which leads to inadequate diagnosis and treatment, generating a negative impact on the quality of life of the child and his or her family⁵⁻⁸. In addition, taking into account various variables in the pediatric population, the verbal expression of this symptom may be limited, so its assessment can be a challenge and the use of internationally endorsed clinical instruments according to the age group and cognitive capacity of each patient is essential⁴⁻⁶.

Various pain scales have been designed to try to quantify pain in children, which contain physiological and behavioral indicators and self-report methods⁴. There are multiple scales used in newborns; the premature infant pain profile (PIPP) scale is the most widely used in the in-hospital setting, both for premature and full-term newborns, and assesses physiological parameters (gestational age, increased heart rate, and decreased oxygen saturation) and behavioral parameters (behavior, frowning, tight eyes, and nasolabial fold)⁹.

In children between 1 month and 3-years-old (or preverbal), the FLACC scale can be used, which stands for face, legs, activity, crying, and comfort. It is a behavioral scale. Of this, there is a revised version that allows the evaluation of pain in children with cognitive disability or neurological compromise that prevents them from verbally expressing pain. The revised face scale is a self-reporting tool and is validated in older children (3 to 7-8 years); Use six-sided drawings with different expressions depending on the degree of pain. In older children with the ability to express their pain numerically, it is recommended to use the verbal numerical scale (self-report), which rates pain from 0 (no pain) progressively to 10 (maximum pain)¹⁰.

The COMFORT-B scale is recommended by the European Society of Paediatric and Neonatal Intensive Care for the assessment of patients under sedation and analgesia in the pediatric intensive care unit (regardless of whether they are on mechanical ventilation or not). It is a behavioral scale that assesses the level of consciousness, calmness-agitation, muscle tone, physical movements, respiratory response, and facial tension¹¹.

There is very limited evidence regarding end-stage symptoms in pediatric patients receiving palliative care; in their study published in 2021, Baumann et al. described the presence of pain in 56% of their terminally ill patients¹². Specifically, cancer patients report the most pain; In the final phase, its prevalence has been described at approximately 75-85%^{12,13}.

Having uncontrollable pain during the terminal stage of life is one of the main fears in patients with incurable conditions¹⁴⁻¹⁶; likewise, very often, the relatives of these children ask doctors to make death as painless as possible, which reduces the risk of complicated grief^{17,18}. Therefore, the past 2 weeks of life, commonly referred to as the terminal phase or imminent death, represent numerous challenges for health professionals¹⁹⁻²¹. Adequate symptomatic management in this phase is essential because it has been proven that a comprehensive palliative intervention helps mitigate pain²²⁻²⁴.

So far, there have been no studies in Latin America on the prevalence of pain in the last weeks of life in pediatric patients, so this study aims to determine this prevalence in patients who died at the Hospital General de México "Dr. Eduardo Liceaga" in the past 5 years.

Materials and methods

A retrospective, observational, and longitudinal study was conducted. The records of all patients over 1 month of age and under 18 years of age who died in the Hospital during the period from January 1, 2016, to December 31, 2021, were included, except those of patients admitted to the emergency room with hospitalization of less than 2 h or with incomplete recording of data on the variables: Gender, main diagnosis, age of death, presence of pain, type of pain based on its chronology and pathophysiology, pain intensity and whether it was evaluated with any tool (scales: FLACC and FLACC-revised, revised face pain scale, COMFORT, PIPP or verbal numerical scale), algological treatment and whether the patient was assessed by the pediatric algology service.

The data were recorded in Excel and exported to the SPSS version 21 program, with which descriptive statistics were carried out using measures of central tendency and dispersion with calculation of simple frequencies and percentages for qualitative variables and mean or median, for quantitative variables, according to their distribution.

According to the Regulations of the General Health Law on health research, title Two, chapter I, article 17, paragraph I of the General Health Law of the United Mexican States, as it is a retrospective study and without intervention in patients, it is considered a risk-free research and does not require the signing of an informed consent.

Results

A total of 638 patients died during their hospitalization in the pediatric service during the study period;

however, 393 files of children under 30 days of age, two of those over 18 years of age and 145 files with incomplete data were excluded. Finally, the records of 98 deceased patients were obtained.

The presence of pain in the last 2 weeks of life was reported in 53.1% of cases; of these, the majority of the population were adolescents (63.4%), followed by pre-schoolers (17.2%), schoolchildren (13.5%) and infants (5.8%), respectively.

The main underlying diagnosis in these patients was oncological, occurring in 50% of the subjects; In the case of non-oncological diseases, infectious causes were the most prevalent (28.3%) (Fig. 1). No patients with cardiological or pneumological diseases were reported.

Of the patients in whom pain was reported, 92.3% had acute pain and only 7.7% had chronic pain. Visceral nociceptive pain represented the most frequent in terms of its pathophysiological basis, occurring in 32.7% of patients, followed by somatic nociceptive pain in 28.8%, mixed pain in 15.4%, and headache in 23.1%.

In less than half of the patients (46.2%), the use of a tool to assess the intensity of pain was reported, with the verbal numerical scale being the most used (34.6%), which was applied to schoolchildren and adolescents. The age group of preschoolers was the one in which a scale for its assessment was proportionally less recorded. Table 1 summarizes the scales used according to the age group.

Of the population studied, severe pain was reported in just under half of the patients (44.2%), followed by moderate pain in 19.3% and mild in 11.5% of the children; Pain intensity was not described in 25% of cases.

In 25% of the patients, the analgesic treatment received was not reported; only one patient was recorded using non-pharmacological measures. Treatment of moderate pain was carried out in equal proportion with paracetamol in combination with some non-steroidal anti-inflammatory drug (NSAID) or paracetamol with opioids, while opioids as the only treatment was the predominant treatment in the severe pain group. No patient received antidepressants or interventional management; nor were there cases of exclusive use of NSAIDs or neuromodulators. Table 2 shows the analgesic treatment received according to the intensity of pain.

Of the total number of patients with a report of pain in their past 2 weeks of life, only 32.7% were evaluated by the Pediatric Algology service; most of them had severe pain (64.7%), followed by moderate pain in 23.5% and mild pain in 11.8%. Opioids were the medications most frequently indicated by the service (58.8%).

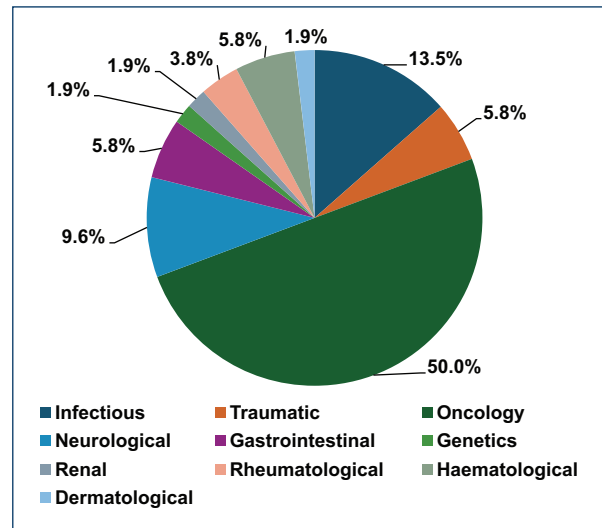


Figure 1. Type of underlying disease in patients with pain in the last 2 weeks of life.

Discussion

Pain has been described as one of the most frequent symptoms in patients during the terminal phase and agony; in our study, it was reported that 53.1% of deceased pediatric patients presented pain in their past 2 weeks of life, similar to the prevalence reported by Baumann et al. in 2021 in their retrospective cohort of 89 pediatric patients, who described a prevalence of pain at the end of life of 56%¹². In general, the literature in the adult and pediatric population has reported the prevalence of pain in the past 2 weeks of life in a range of 45-80%^{12-14,19}.

The symptoms that occur in the terminal phase of a patient and their intensity are more frequently influenced by the etiology of the disease they suffer, with those children with oncological diagnoses reporting greater pain, representing 75-85% of the underlying pathologies described in patients with pain at the end of life^{12,13}. This percentage is much higher than that found in our study, where only 50% of oncological diagnoses were reported; This may be related to the fact that the hospital treats proportionally more children with non-oncological diagnoses.

On the other hand, it has been reported that pain occurs less frequently in patients with cardiological or respiratory diseases, due to the prevalence of dyspnea¹². In our study, no pain was reported in patients with these conditions.

The evaluation of pain during the end of life in pediatrics is a challenge for medical personnel since, depending on their development, cognitive capacity and clinical condition of the patient, the verbal expression of this symptom

Table 1. Tool used for the assessment of pain according to age group

Age group	Pain assessment tool used (%)						
	No report	FLACC o FLACC-R	Revised face scale	Numerical verbal scale	Confort	PIPP	
Infant (1 month-2 years)	1 (1.9)	-	-	-	1 (1.9)	1 (1.9)	3 (5.8)
Pre-school (2-5 years)	6 (11.5)	2 (3.8)	1 (1.9)	-	-	-	9 (17.2)
Schoolchildren (6-12 years)	3 (5.8)	-	-	4 (7.7)	-	-	7 (13.5)
Adolescent (over 12 years old)	18 (34.6)	-	1 (1.9)	14 (26.9)	-	-	33 (63.4)
Total	28 (53.8)	2 (3.8)	2 (3.8)	18 (34.6)	1 (1.9)	1 (1.9)	52 (100)

FLACC: face, legs, activity, cry, consolability; PIPP: premature infant pain profile.

Table 2. Analgesic treatment according to the intensity of the pain

Algological treatment	Intensity of pain (%)				Total
	No report	Slight	Moderate	Severo	
No report	-	3 (5.8)	-	-	3 (5.8)
Non-pharmacological	-	1 (1.9)	-	-	1 (1.9)
Paracetamol	3 (5.8)	1 (1.9)	1 (1.9)	1 (1.9)	6 (11.5)
Opioids	1 (1.9)	-	2 (3.8)	13 (25)	16 (30.8)
Paracetamol + NSAID	1 (1.9)	1 (1.9)	3 (5.8)	-	5 (9.6)
Paracetamol + Opioids	6 (11.5)	-	3 (5.8)	4 (7.7)	13 (25)
Paracetamol + NSAID + opioids	2 (3.8)	-	-	2 (3.8)	4 (7.7)
Opioids+neuromodulator	-	-	1 (1.9)	3 (5.8)	4 (7.7)
Total	13 (25)	6 (11.5)	10 (19.3)	23 (44.2)	52 (100)

NSAID: nonsteroidal anti-inflammatory drugs.

may be limited, which is why the use of internationally endorsed clinimetric instruments according to the age group and cognitive capacity of each patient is essential for its assessment⁴. In our study, it was found that a pain rating scale was used in less than half of the patients, and preschoolers were the age group in which the use of any of these tools was proportionally less reported. This shows that, despite the existence of validated clinimetric instruments for the efficient assessment of pain at different ages, their use in our setting is still infrequent. This highlights the importance of educating physicians and residents in training regarding pain assessment instruments in this population, so that a more comprehensive and objective approach can be carried out, not only for the diagnosis of pain, but also for its follow-up and surveillance of response to the treatment established.

In addition, as it is described as an unpleasant sensation and being one of the symptoms that generates the most suffering, it is common for patients and their families to express their desire to avoid or mitigate it as much as possible, especially in the terminal phase¹⁴⁻¹⁸. Its management in the final phase can be challenging, with the literature even reporting the requirement for the use of three or more drugs for adequate control¹². Therefore, it is

essential that patients are evaluated by specialists in pain medicine, especially in cases of pain of moderate-to-severe intensity or pain that is difficult to control. In this study, only about a third of the patients were required to be evaluated by the Pediatric Algology group; with the above, it is important to highlight the importance of sensitizing the treating services regarding the great value of an approach by said service to guarantee comprehensive treatment and minimize suffering and agony in these patients.

Finally, in general, opioids have been described as the most commonly used medications in up to 74% of terminally ill patients¹², a frequency similar to that found in our study where 71.2% of children with pain were managed with opioids (alone or in combination with other drugs). This is probably related to the severity of the symptom at the end of life, with the requirement of high-potency therapies to achieve adequate control.

Conclusions

Pain is a frequent symptom in the past 2 weeks of life and sometimes its identification can be difficult, especially in the pediatric population, so the use of validated instruments for its evaluation is essential. In the final phase

of the disease, pain is usually difficult to manage and its approach must be individualized, taking into account the age of each child, their clinical characteristics, the characteristics of the pain and the phase of the disease in which they are. Pain relief has been closely related to the Human Right to health, making it an ethical obligation of health professionals and a fundamental pillar of good medical practice. Therefore, a timely assessment by the Pediatric Algology service in those patients who present it is essential, in such a way that comprehensive management and adequate control of the symptom can be guaranteed, thus reducing the suffering, not only of the patient but also of his or her family.

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Conflicts of interest

The authors declare no conflicts of interest.

Ethical disclosures

Protection of human and animal subjects. The authors declare that no experiments were performed on humans or animals for this study.

Confidentiality of data. The authors declare that no patient data appear in this article.

Right to privacy and informed consent. The authors have obtained Ethics Committee approval for the analysis and release of routinely collected clinical data. Informed consent from patients was not required as this was a retrospective observational study.

Use of artificial intelligence for generating text. The authors declare that they have not used any type of generative artificial intelligence for the writing of this manuscript, nor for the creation of images, graphics, tables, or their corresponding captions.

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