

Pediatric Palliative Care: Historical Origins and a Glimpse into Ethical Issues



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Abstract

At the beginning of the 20th century, infant mortality in Europe was extremely high, primarily due to malnutrition and untreatable diseases. Additionally, children's pain and suffering were often ignored due to a lack of resources and cultural beliefs that underestimated their perception of these symptoms. From the second half of the last century onwards, thanks to advances in biomedical and biotechnological fields and general improvements in living conditions, this "massacre of innocents" has been significantly reduced. This has led to a prolongation of life in cases of chronic or terminal illnesses, along with the potential for prolonged suffering for the patient and their loved ones. The recognition of pain and suffering in children and our moral duty to protect the most vulnerable, combined with an evolution in medical ethics that values the concepts of well-being and quality of life, has led to the development of Pediatric Palliative Care (PPC). However, access to these practices is not always guaranteed, necessitating an ethical reflection on their importance to promote their dissemination and the communication and relational approaches. New philosophical transformations are hoped for, aiming to promote an open dialogue on sensitive topics such as illness and death in the pediatric field.

Keywords: History of Medicine; History of Pediatric Palliative Care; Medical Ethics; Ethics of Pediatric Palliative Care; History of Medical Ethics

Abbreviations: PC: Palliative Care; PPC: Pediatric Palliative Care; MAD: Medically Assisted Death

Introduction

The field of Pediatric Palliative Care (PPC) today encounters broad ethical endorsement, to the extent that the World Health Organization defines it as a human right and an ethical responsibility of healthcare systems [1,2]. Its historical origins are relatively recent, aligning with the progress of medicine and cultural transformations in society, transitioning from a notion of the inevitability of pain and suffering, considered unconscious in the very young, to recognizing the right of pediatric patients and their families to experience the various stages of illness, including

its final phase, with the best possible quality of life. Nonetheless, PPC remains a field that needs encouragement and support. This is due to limited medical resources, traditionally directed towards active treatment of diseases rather than investing in comprehensive end-of-life support, and a perspective that tends to stigmatize and remove the process of dying in its final stages. Retracing the major milestones that have led to the definition of PPC and highlighting the persistent challenges can serve as a useful tool for conducting a historical-ethical reflection on this important and sensitive field.

The Historical dawn

At the beginning of the 20th century, in many European countries nearly half of all children died before reaching the age of 15 [3]. This significant loss of human lives occurred within a commonly accepted phenomenon we can term the “massacre of innocents”: given the high birth rate, almost every family experienced the loss of a child at least once, considering it an inevitable event. This context was attributable to both the nutritional deficiencies of an insufficient or inadequate diet and to diseases that had no effective treatments at the time [4]. Furthermore, due to cultural reasons and limited clinical and therapeutic resources, the pain and suffering of young patients were often ignored. The clinical disregard for pediatric pain was due to two main factors. First, these symptoms were generally perceived as an intrinsic aspect of diseases and, in advanced stages, of the dying process itself. Additionally, while adults’ agony was considered a trial to overcome or a sign of destiny, possibly spiritually beneficial, it was believed that children possessed a special ability to adapt to “being unwell” and to tolerate discomfort due to a high pain threshold [5], or even their unawareness of pain itself [6] due to a presumed “neurological immaturity,” meaning an incapacity of the nerve pathways to transmit painful stimuli and of the cortical function to recall painful experiences [7]. Analgesics were rarely administered to hospitalized children [8], despite diagnoses of traumatic foot amputation, excision of a neck mass, and heminephrectomy [5]. Anesthesia was not even used for surgical procedures [7], such as thoracotomies, ligation of the ductus arteriosus, tonsillectomies, circumcisions, and tooth extractions [9].

The dire clinical situation faced by children in the past gradually improved until the mid-20th century due to a series of advancements in hygiene and sanitation, as well as partial general improvements in living conditions. A decisive step was taken with the discovery of the pathogens causing many common diseases, which allowed for the introduction of specific vaccines. Through large-scale vaccination campaigns, the incidence of diseases such as smallpox and diphtheria, which claimed a high number of young lives, drastically decreased. Infant mortality also significantly declined due to a greater understanding of the pathogenesis of infectious diseases and the adoption of public hygiene practices, among which water purification and milk sterilization played a prominent role.

Starting from the second half of the last century, the positive trend in survival rates accelerated further due to new medical and pharmaceutical advancements. The use of antibiotics, foremost among them penicillin, marked a watershed moment, becoming a milestone in medical practice and allowing for the effective treatment of bacterial infections that were previously often lethal. The adoption of antimicrobial agents revolutionized the treatment of these infections, drastically reducing the mortality associated with widely prevalent diseases such as tuberculosis

and cholera [10]. Intravenous infusions made it possible to deliver essential fluids and nutrients directly into the bloodstream, a crucial aspect in the treatment of severely ill or malnourished children. The improvement in the functioning of negative pressure ventilation systems, such as the “iron lungs” widely used during polio epidemics to assist patients with respiratory paralysis, and the refinement of positive pressure systems, represented another significant advance, particularly in the treatment of respiratory failures. These advancements offered greater hope of survival for many patients who would not have otherwise survived. It is worth noting that in 1951, Copenhagen was struck by a severe polio epidemic, which led to the hospitalization of up to 50 patients per day, with more than two-thirds dying from respiratory failure. Thanks to positive pressure ventilation and tracheotomy interventions, mortality drastically decreased, from 87% to about 40%, almost overnight [11].

However, as often happens, extraordinary advancements bring about new challenges. For pediatric patients, as well as for adults, the ability to prolong life in the case of chronic or terminal illnesses often resulted in an extension of the dying process, bringing with it the potential for prolonged suffering for the patient and their loved ones [12]. Gradually, there was a shift towards focusing on the treatment of physical pain and alleviating the psychological, emotional, and existential suffering associated with a prolonged morbid condition, with the aim of contributing to the well-being of the patient and their family throughout the illness journey until the very end. As is well known, Palliative Care (PC), a term coined by Balfour Mount in Montreal [13], was significantly promoted by Cicely Saunders at the St Joseph’s Hospice in Hackney, London [14], while the first dedicated hospice is attributed to Florence Wald in Connecticut [15,16]. The specific field and expansion of PPC owe much to the development of pediatric specialties such as oncology and emergency pediatrics, along with a growing recognition by clinicians and society at large that children (including neonates) were not immune to experiencing pain and suffering and, despite their young age, were capable of being aware of their distressed physical and emotional state [17]. Towards the end of the 1970s, along with the emphasis on minimizing invasive procedures, palliative care strategies in pediatrics began to spread among the clinical practices of pediatricians [18], including the use of sedation or anesthesia to alleviate pain in minor surgical interventions [19].

In the following decade, the disparity in treatment between children and adults regarding anesthesia and analgesia led to a statement from the American Academy of Pediatrics (Committee on Fetus and Newborn, Committee on Drugs, Section on Anesthesiology, Section on Surgery), which set the direction to address this gap and thus ensure the administration of medications for the youngest patients as well [7]. Additionally, these new anesthetic resources were reflected in the literature: chapters dedicated to end-of-life care began yet to find a dedicated space within pediatric textbooks [20]. Furthermore, the 1980s

also saw the emergence of the first pediatric hospices, such as Helen House in England [21]. However, while adult hospices allowed patients to stay until death, initially, pediatric hospices only accommodated patients during acute phases. This period still reflected a historical moment where the intention to treat pain and alleviate suffering in children was often seen more as a form of support and relief for their parents rather than for the patients themselves: even though there was growing awareness of children's symptom perception, the primary focus remained on safeguarding the well-being of adults.

What became clear during that period was that the issue of pain and suffering does not belong solely to the physical dimension, which physicians strive to quantify scientifically and address clinically. An important part is instead tied to the unique subjectivity of the individual, who, based on their characteristics, experiences the specific condition of illness. This broader perspective on the different ways of perceiving symptoms led to the conviction that it was necessary to create teams of experts who, according to their various disciplinary assessments, would be available to the patient and their family. Thus, multidisciplinary teams for PPC were established [22,23].

The recognition of PPC as a distinct field of study was solidified starting in the 1990s, when the American Academy of Pediatrics adapted PC to meet the specific needs of the pediatric context [24]. The Oxford Textbook of Palliative Medicine and the Journal of Palliative Care dedicated sections and special issues specifically to PPC [25].

The Ethical Impact

From the perspective of medical ethics, in the Hippocratic view of traditional medicine, a good physician is defined as one who pursues clinical good, protects health, and strives to preserve the biological life of the patient. This conception is based on the ethical assumption that identifies life as a good and death as bad. Consequently, if there is a cure for a disease, the physician is morally obligated to act for the patient's benefit (principle of beneficence). In past eras, however, medicine was not sufficiently advanced to effectively combat diseases, and often, the necessary economic resources were not available to ensure adequate medical care and a dignified standard of living. The only possible approach was to accept death caused by diseases, sometimes imagining an afterlife that could compensate for earthly losses, especially when these were premature. Children, in particular, were most affected by this situation, being extremely vulnerable. High infant mortality was seen as an inevitable aspect of the struggle for survival, almost a form of natural selection in which the strongest would survive, those who in the future could contribute to the sustenance of the family.

Daily life was so burdensome that the idea of living without pain and suffering was inconceivable. These symptoms were perceived as inseparable from existence itself, tied not only to

diseases but to the very essence of life, including the process of dying. In that context, adequate medications to treat pain were lacking, and the resource for addressing suffering was often of a religious nature. As we have emphasized, children in particular paid a high price for a mistaken perception of their ability to endure pain, which was believed to be high or even nonexistent. Consequently, the few medications available for pain treatment were rarely administered to children.

As noted, with the advancement of medical progress, especially from the second half of the last century, the situation began to change. Medicine developed new life-sustaining capabilities, and simultaneously, societies moved beyond periods of poverty, wars, and famines. These changes led to an increase in life expectancy and the transformation of medicine into a right guaranteed by significant legal developments. In some cases, this shift even led to the opposite extreme: an excess of medical intervention, which began to be critically evaluated as aggressive treatment rather than therapeutic benefit. In certain circumstances, the medical outcome resulted in a condition of life so compromised that the only apparent solution was the termination of life itself through withdrawing life-sustaining treatments, as well as fueling the bioethical debate on Medically Assisted Death (MAD: euthanasia, and medically assisted suicide).

These developments have shifted the focus from mere survival to living well, highlighting the importance of well-being. The goal was no longer just mere survival, but a quality life. The belief spread that the value of life lies not only in its biological duration but in its biographical aspects. This evolution has promoted the development of PC, where the focus is on ensuring that patients live without pain and suffering, in line with the prohibition of aggressive and futile treatment: medicine should be an opportunity to improve life, not an intervention that compromises its quality. Regarding children, the erroneous belief that they were less sensitive or immune to pain and suffering has been overcome. Today, thanks to cultural and legal advancements, they are recognized as individuals deserving of medical attention that fully respects their sensitivity. The prevention and treatment of pain have thus become integral to our approach to life, decisively entering clinical practices, including those directed at children. Ideally, PPC now enjoys widespread recognition, although some critical issues remain, both of a philosophical-cultural nature and practical, related to its concrete implementation.

As highlighted, in Europe, as well as in all industrialized countries, infant mortality has reached increasingly lower levels thanks to advances in biomedical and biotechnological fields. However, we have not yet succeeded in eradicating the severe, chronic, and complex pathological conditions that affect millions of children worldwide. A portion of this large population is potentially eligible for PPC, considering that knowledge of these practices is increasingly widespread among healthcare professionals and the general public. The need for PPC is real,

but it is based on the understanding that there is a possibility to respond to that need and on having the concrete resources to implement it [26].

In many countries, efforts are being made to improve the provision and quality of PPC through targeted healthcare policies, the training of healthcare professionals, and the development of specific care networks. Nevertheless, significant disparities in access persist [27]. Healthcare resources are always limited, and their allocation requires careful ethical analysis according to the principle of justice and equity. The central moral question is: why invest in PPC instead of curing children who can be healed? Indeed, while we recognize PPC as an ethical good, could it be considered a lesser good compared to the possibility of ensuring a future for individual human life, as well as for the species? To emphasize the importance of PPC, it is crucial to reiterate their goal, which is to treat the symptoms of the pathology: this improves the quality of life for young patients and their families during the difficult journey of illness and end-of-life [28]. The value attributed not only to how long one lives but also to how one lives becomes the pivotal point around which the transformation of medicine revolves, from focusing on safeguarding mere biological life to considering the decisive concepts of well-being and biographical life. Such an ethical evolution can guide appropriate choices in the allocation of available resources, balancing the needs related to active treatment and PC, and ensuring the full integration of PPC into national healthcare systems. The adoption of well-structured healthcare measures can facilitate the qualification of professionals, the availability of essential palliative medications, and support for families. In this context, new digital medicine technology offers unprecedented opportunities to implement PPC, facilitating the dissemination of these services to remote or underserved areas. For example, it can support patients and their families through remote consultations and contribute to staff training [29].

Achieving the goal of including PPC in national investment plans with an institutionally recognized role is only the first step. It is important to note that PPC should be implemented early to provide care and support to the child and their family throughout the course of the illness. Timely addressing changes in conditions can prevent and alleviate the suffering associated with the severity of the context. For this to be realized, it is crucial to establish a close connection between the hospital and the community. Pediatric patients with PPC needs should be identified in the hospital setting and then transferred to their homes or appropriate facilities, ensuring continuity of care. In the community, it is essential to enhance home care services to offer the opportunity to spend the illness period, including its final stages, surrounded by the warmth of one's home. Additionally, the presence of dedicated pediatric hospices is crucial, where complex medical care can be combined with psychological, emotional, and spiritual support [30].

In a world that tends to exalt vitality, performance, and success, illness and death are often considered taboo subjects, to be avoided or treated with euphemisms, especially when it comes to children [31]. Whereas in the past these experiences were "familiar," frequently occurring and mostly within the home, today they are effectively removed from our daily lives: illness itself has been replaced by treatment (there is no longer a "sick child" but rather a "child undergoing treatment"), and death mostly occurs away from our personal environment. Additionally, talking and discussing such events can be frightening, generating fear and anxiety, forcing us to become aware of our own mortality and fragility, and for some, may even be considered ominous.

In the healthcare dimension, these interpretations can translate into difficulties for healthcare professionals in transparently communicating an adverse diagnosis and prognosis, in an attempt to protect those with parental responsibility from news that will likely disrupt their lives. However, this approach risks compromising the pursuit of informed decision-making [32]. The medical team should always aim to improve the physical, mental, and emotional health of the sick child and their family, and be capable of proposing therapeutic opportunities that can offer not only life extension but also optimization of its quality by controlling symptoms as much as possible. Therefore, clear and comprehensive communication about clinical conditions and their progression, possible treatment options, including risks and potential side effects [33], should be provided to ensure fully informed consent or dissent.

Considering the sensitivity of the context, the conversation should be conducted with careful sensitivity and empathy. Furthermore, it should involve the pediatric patient in both the informative and decision-making phases, adapting the communication, provided in collaboration with child psychology experts, to the child's age and capacity [34,35]. The inclusive approach towards the pediatric patient has been debated over time and still maintains aspects that can elicit differing opinions [36]. Can a child truly be capable of self-determination based on the ethical principle of individual autonomy, namely, of determining their own well-being in terms of health and illness? Overcoming the usual notion of the minor as an "incompetent child" to be shielded from a reality that might frighten them requires a significant philosophical effort aimed at understanding how, in attempting to protect them from fear and anxiety, they are deprived of the tools to make sense of their illness and treatment situation, thereby increasing feelings of isolation and fear [37].

Additionally, beyond moving away from the conventional approach, healthcare professionals may also face challenges in relating to young patients, adopting appropriate listening and interaction methods. In this regard, proper training can enable the acquisition of not only technical and clinical skills but also communication and relational skills with a special focus on the pediatric patient. This includes learning to explain complex

concepts in an understandable manner; adapting language and information to the child's age and level of comprehension [38]. Healthcare facilities themselves play an important role in these interactions: thoughtful design and organization of hospitals, such as incorporating child-friendly spaces where children can feel comfortable, would facilitate establishing the right relationship with the pediatric patient [39].

A cultural transformation in the way we approach death, even when it affects a child due to trauma or disease, represents a necessary philosophical shift to recognize the true value of PPC. Furthermore, the ethics of PPC can open up a broad multidisciplinary debate on end-of-life bioethics for pediatric patients. This includes a reflection on MAD in pediatrics, once its presumed opposition to palliative interventions has been overcome, and without fearing that this analysis might undermine our support for PPC [40].

Conclusion

Looking back at our past, many advancements have been made for the benefit of pediatric patients, culminating in the creation of the field of PPC. However, for these practices to gain proper recognition and integration into the healthcare system, collective and collaborative scientific efforts among various involved sectors and specific supportive policies are still necessary. It is essential to promote actions that encourage PPC, acknowledging that pediatric patients and their families have the right to face the different stages of illness without pain and suffering, including support for families even after bereavement. To achieve this goal, it is crucial to reduce the stigma often associated with end-of-life care and to emphasize concepts such as well-being and quality of life. Only through concerted efforts and a multidisciplinary vision of care can we ensure the full promotion and realization of this transversal dimension of care, defined as PPC, ensuring that every child, along with their loved ones, receives the physical, psychological, emotional, and spiritual support they need.

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