Basic principles of Palliative Care on Pediatrics: A narrative review

Principios básicos de cuidados paliativos en pediatría: una revisión narrativa

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ABSTRACT

Palliative care is a topic that is gaining more and more relevance. This therapy benefits the patient throughout their illness, for that reason, the scientific community is becoming aware of the importance of including such treatments in basic health services. Unfortunately, only some of the developed countries manage to have decent assistance in this type of care, and that is why governments and world organizations are taking more ambitious objectives in order to improve health quality even more.

The evidence presented in this article shows the future possibilities of PC, focusing its attention on pediatric patients and their families, as well as the guidelines to be followed by the professional team to guarantee a complete and satisfactory approach.

Keywords: palliative care, pediatrics, end of life care, pain relief, hospice.

INTRODUCTION

Palliative medicine is a largely unknown field, and it is even more so when it is limited to the pediatric age. Currently it is thought to be restricted to agony, to keep the patient sedate at the time of death. Nothing is further from reality, Palliative Care (PC) provides well-being and support to the patient and their families, and they ensure that the patient is conscious, free of pain and in the event of death, to help dying with dignity. They don't speed up or stop the dying process; they just give the patient a better quality of life.

Palliative Care can be given at the same time as treatments intended to cure or treat disease. PC can start when the disease is diagnosed, throughout treatment, follow-up, and at the end of life. They may accompany the patient throughout his illness, without neglecting any aspect (physical, psychological, social and spiritual), being all equally important.

Children are special patients, they do not understand death and pain in the same way as adults. To this fact adds the ethical problems that arise about who should make such tough decisions. Therefore it is important to adequately inform the family and the patient to avoid suffering and uncertainty, and also accompanying them properly.

For all these reasons, the authors have tried to gather information relevant to palliative care in children, given that it is a subject of great ignorance and where health professionals require a great deal of specialized training.

RESUMEN

Los cuidados paliativos son un tema cada vez más de actualidad. Esta terapéutica beneficia al paciente a lo largo de toda su enfermedad, por lo que se empieza a tomar conciencia de la importancia de incluirlos en los servicios básicos de salud. Por desgracia sólo algunos de los países desarrollados consiguen tener una asistencia digna en este tipo de cuidados, y es por ello que gobiernos y organizaciones mundiales toman objetivos más ambiciosos con el fin de mejorar todavía más la calidad sanitaria.

La evidencia presentada en el presente artículo muestra las posibilidades futuras de los cuidados paliativos, centrando su atención en los pacientes pediátricos y sus familias, así como las directrices a seguir por parte del equipo profesional para garantizar un abordaje completo y satisfactorio.

Palabras clave: cuidados paliativos, pediatría, cuidados al final de la vida, alivio del dolor, hospicio.

MATERIALS AND METHODS

A bibliographic search was carried out to date in PubMed. The search strategy used the following keywords: *palliative care, pediatrics, and their combination, end of life care, hospice, pain relief, terminal care, agony, pediatric oncology, quality life, acute and chronic pain*. Only articles available in English or Spanish were included. The search has focused on the last 10 years, and if publications of interest do not appear in that period, an attempt has been made to find the most recent and best quality experiences. Articles containing information exclusively on adults or whose results could not be extrapolated were excluded.

Children from 0 to 19 years of age have been taken as a reference for pediatric patients, which is the classification that the WHO follows in palliative care.

RESULTS

PALLIATIVE CARE IN PEDIATRICS

Definition

Palliative care helps people with serious illnesses feel better by preventing or treating symptoms and side effects of illness and treatment.

The WHO defines palliative care in children as “active total care of the body, mind and spirit that also implies giving support to the family”. This same organization in 1999 marks a milestone in palliative medicine, urging that palliative treatment should begin when the child is diagnosed for the first time, and continue throughout the course of the disease[1].

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Health personnel must assess and alleviate the physical, psychological, social, emotional and spiritual problems of the child. This requires a broad multidisciplinary approach not restricted only to the hospital setting, they must also take place in the child's home. All this makes the child have a better quality of life[2].

Epidemiology

The following data were extracted from the Global Atlas of Palliative Care 2020[3]:

More than 97% of children aged 0-19 who need palliative care live in low- and middle-income countries. Children with HIV / AIDS and congenital malformations are 46%, followed by birth trauma (18%) and injuries (16%). Cancer lags far behind all of these (4.1%).

In 2017, 45.3% of deaths in the world required palliative care. 40% were 70 years or older and only 7% were children (0-19 years). In this same year it was estimated that almost 4 million children needed palliative care.

Reality and barriers

A study was carried out to find out when the PC started. 54.4% of oncopediatric patients had received palliative services before death[4].

The mean time from cancer diagnosis to palliative consultation was 509.6 days. Therefore, it did not occur at the time of diagnosis as recommended by the WHO.

In part it is due to the fear of the professionals themselves; starting palliative care so early may provoke a feeling of hopelessness both in the child and the family[5].

Related to this, a study of 1.2 million subjects revealed that between 33% to 38% of patients received treatment with curative intent, but with no beneficial effects, in the last 6 months of life[6]. It is better to alleviate and not be stubborn in these cases. Finding the best comfort conditions for the patient.

In addition to the above, there are numerous barriers to the effective implementation of Palliative Care: policy (many countries do not include the need for this care in their legislation), education (professionals around the world are poorly trained in these subjects), availability of medicines (many countries have limited access to opioids. Developed countries consume 90% of painkillers3. If this is added that more than 97% of the children who need PC are in the latter countries), implementation, need for health personnel, psychological, social and cultural (people tend to avoid everything associated with the word death), financial...

Common Symptoms

Pain is the most common symptom. Another frequent symptom in the last phase is dyspnea[7].

There are also constitutional symptoms (anorexia and asthenia), digestive (vomiting and constipation), neurological (seizures, agitation and insomnia), dermatological (pruritus) and urological (urinary tract infection and incontinence).

Palliative Treatments

PCs can and should coexist with treatment and are important from diagnosis.

Many palliativists follow the SPIKES8 method:

1. S (*set up*)	set up the conversation.
2. P (*perceptions*)	to evaluate the patient’s perceptions.
3. I (*invitation*)	obtain patient consent.
4. K (*knowledge*)	to give information to the patient.
5. E (*emotions*)	addressing the patient’s emotions with an empathetic response.
6. S (*strategize and summarize*)	establish a strategy and summarize.

RESULTS

Ethics And Autonomy

There is a question we must ask ourselves: who should decide? The decision should be a joint one between the patient, the relatives and the healthcare personnel. The child, if he/she is somewhat older, has the right to know the situation and to be well informed[9]. The child, regardless of age, must be adequately informed and adapted to his or her age.

Spirituality

A fundamental theme in PC is spirituality. Caregivers should bring peace to the patient and family members. Findings suggest that spiritual care has positive effects[10].

Death Awareness

Seriously ill children who know that death is irreversible are afraid of not leaving a legacy, of being forgotten. They also tend to think about death, even if they do not communicate it[11].

From 18 months to 5 years of age, children do not understand the concept of the future, they live only in the present and associate death with sleep and immobility. From 5 to 10 years of age, they begin to be curious about death, and it implies separation not only from parents but also from friends and school. The irreversible nature of death is acquired around the age of 9 years, especially the fear of the death of parents appears[12].

Family Experience And Bereavement

Anxiety is a frequent symptom in the family in the last stage of the children's illness, because of the severe suffering they see their children going through[13].

In Sweden, a study was conducted of parents who experienced the death of a child between 1992 and 1997 and were asked a questionnaire about whether they had talked to their children about the death. Of 449 families, none of the 147 who talked to their children about the death had regrets. However, 69 of the 258 parents who did not talk to their children about it regretted it[14].

Grief begins long before the death (*anticipatory grief*); when the idea that your relative is going to die irremediably becomes conscious. This process is exacerbated in the moments closest to the patient's death (acute grief) and can last up to 2 years (more in cases of *complicated grief*).

It should be explained to the family members about this reality and give them support and recommendations to overcome this process[15].

The problem occurs when this grief becomes complicated. It is essential to see the risk factors by which a normal bereavement can become a pathological bereavement[16]: death of children or adolescents, unexpected or sudden death, being even worse traumatic (accidents) or stigmatized (suicide, AIDS...), prolonged and painful illness, history of previous unresolved losses, simultaneous stressors (low economic level, family problems...), lonely or distant people, insufficient social support, families with insufficient levels of communication and ability to express their feelings, belief that more could have been done for the patient...

One study states that 94% of mothers, 87% of fathers and 69% of siblings reported substantial changes in their lives and priorities. They also report a higher prevalence of sadness and depression[17].

Another study, which took data between 1999 and 2000 in children with cancer, reports that 36% of the families did not receive any conversation about PC[13].

ONCOPEDIATRICS

Pediatric cancer and its treatment have improved substantially in recent decades, increasing survival and improving prognosis. Despite all this progress and as a consequence of the search to improve the quality of life of these patients, preventing and treating their symptoms, a strong integration of palliative care in oncopediatrics has emerged[18].

Evidence confirms that good palliative treatment from early stages of the disease helps these patients, as well as their families, considerably[5].

One of the main recommendations is doctor-patient communication, as well as focusing on the family[19], talking and explaining everything they need, as this increases patients' wishes for their families to make appropriate decisions as needed, improves patients' understanding of end-of- life options, increases the likelihood of limiting futile treatment, and increases the family's ability to carry out their children's wishes.

PAIN IN PEDIATRICS

The International Association for the Study of Pain defined pain as "an unpleasant sensory and emotional experience, associated with actual or potential tissue damage." It is a multidimensional, subjective phenomenon that requires comprehensive care.

Pain in pediatrics is not evaluated and treated efficiently[20]. Good pain control in pediatric patients is vitally important so as not to create future trauma.

Types Of Pain

Pain can be acute, chronic, or a combination of acute over chronic. Furthermore, it was found that pain increases with age and is more common in girls20.

Chronic pain is defined as any prolonged pain that lasts longer than expected; usually the benchmark is set at 3 months[21]. It can also be any recurring pain that occurs at least 3 times over a 3-month period. King et al. report that the most frequent recurrent chronic pain in children is headache, followed by abdominal pain[22].

Pain Assessment

A correct evaluation of pain facilitates the diagnosis and follow-up of the disease. It must be continuous since the pathological process is a continuum and they vary. To make a correct anamnesis the following points should be touched[1]: evaluate (children can experience pain and not transmit it in the same way as adults), locate (complete examination, noting grimaces or contractions), contextualize (take into account social and family factors of the child), document (use pain scales based on cultural context), assess the effectiveness of the treatment and modify the treatment plan if necessary.
Therefore, information comes in 3 ways: self-report, behavior of the patient and physiological indicators[20].

Pediatrics covers a very wide age range; It is not the same to evaluate a newborn as an adolescent, therefore, you have to look at different details[12]:

In premature infants, infants and in early childhood children will not speak, therefore it is vitally important to look at their behavior and their physiological indicators.

In schoolchildren and preschoolers it can be seen that they are already capable of expressing pain, although with limitations.

Crying is more typical when the pain is brief, however, when the pain is persistent, motor disorders, disinterest in the environment, less ability to concentrate and sleep disorders are often seen[1].

Children over 6/7 years of age are already able to correctly verbalize the presence of pain, its location and define its intensity, in a similar way to adults.

There is no single scale that evaluates intensity for all ages and all types of pain: Numeric Rating Scale (NRS), Visual Analogue Scale (VAS), VAS pictorial adaptations, Faces Pain Scale-Revised (FPS-R)[23]. All of these scales can be used to see the evolution of the child's pain and illness over time.

Pain Control

Pain control brings a series of benefits to the child such as: improved satisfaction, increased trust in healthcare personnel, improved quality of life, improved sleep, protects against depression and reduces the cost of overall treatment.

For pain control there are non-pharmacological guidelines and pharmacological guidelines.

Non-pharmacological guidelines

These measures should complement the pharmacological treatment but not replace it. The first thing would be the support methods: provide good psycho-emotional assistance to children. Reinforce empathy and give them participation in the decisions that are made.

There are also cognitive methods that try to influence the child's thoughts, the more distracted in an activity he is, the less pain he will feel.

Finally, there are physical methods, which are of vital importance in childhood, such as caressing, cradling, taking in arms.

Pharmacological guidelines

The WHO Analgesic Ladder is followed. The first rung is a non-opioid analgesic, the second rung is a minor opioid along with NSAIDs, and the third will be a major opioid along with NSAIDs.

Doses should be given at set times and not only when there is pain, unless the painful episodes are with a very wide frequency range. In addition, rescue doses are added in case of breakthrough pain. Patient Controlled Analgesia (PCA) is useful in children over 7 years of age for rescue pain relievers; after each use there is a lockout period. This way, the child is protected as much as possible from pain.

In pediatrics it is of vital importance to choose a good route of administration. It has to be the simplest, most effective and least painful way.

TREATMENT IN THE LAST DAYS. AGONY

This section represents an important multidisciplinary challenge[24]. Given the nature of this phase, it is essential to recognize and diagnose this process, understand the characteristics of the suffering of the patient, provide the best care and support the family and, as well as differentiate the terminal phase with a relapse.

To complete the care of the patient and his family, it is essential to take care of 3 sections[16]: physical, psychological and social care.

CHILD EUTHANASIA

The debate on infant euthanasia goes back a long way, with a major precedent being the case of the newborn Bente Hindriks in 2001. Born with a rare and fatal skin disease, both relatives and professionals made the decision to perform active euthanasia. This caused an international uproar due to the legal consequences of the acts, establishing as a legal basis the Groningen Protocol, the purpose of which was to establish the criteria under which legal action could not be taken against the team responsible[25]: the diagnosis and prognosis must be confirmed, there must be unbearable and hopeless suffering, there must be confirmation by a second opinion from an independent physician, both parents must give informed consent and the procedure must be carried out carefully and in accordance with medical standards.

The Spanish Organic Law regulating euthanasia defines euthanasia as the deliberate act of ending the life of a person, produced by the express will of the person him/herself and with the aim of avoiding suffering. However, in Spain this law requires the applicant to be of legal age as an indispensable requirement[26].
There are very few countries that have regularized this process, but only Belgium contemplates child euthanasia since the amendment of its law in 2014.

This is a precedent that reinforces the idea that the minor is competent in his or her condition and decision to die.

DISCUSSION

It is observed that the vast majority of children in need of PC live in low- and middle-income countries (>97%), so it can be considered that living in such a country is a risk factor for needing palliative care.

Another problem we found is late referral to palliative care due to the reluctance of the health care providers themselves and the "hopelessness" that this could provoke in the families. The evidence shows that early treatment in palliative care, from the moment of diagnosis, increases the quality of life of the child and the satisfaction of the family considerably.

There is a great need to educate healthcare personnel and patients about the need for PCs. Myths must be debunked and taught to be compatible with the different cultures and religions that exist throughout the world. All people have the right not to suffer, to have a good quality of life even when ill, and in the event of illness, to have a dignified and comfortable death.

One of the most debated ethical issues is the autonomy and competence of the child's choice. How much weight should be given to the child's opinion? How should the child's maturity be assessed?

These are undoubtedly big questions that are frequently asked in this area. It should be better regulated and not value so much the numerical age, but the maturity of each child.

In terms of pain, health care workers should be better trained to recognize the suffering of the child in each age range, use scales and treat appropriately. Old myths such as addiction should be dismantled and the patient's pain should be adequately controlled to improve their quality of life.

Non-pharmacological therapies such as games, visits from superheroes, visits from school friends... help the child to escape from pain and illness and to enjoy as much as possible. These types of therapies acquire special value in childhood, helping the child to develop properly.

CONCLUSIONS

Despite medical advances, pediatric palliative patients still continue to suffer significantly.

One of the most important goals of PCs focuses on the need to initiate this aspect of care as soon as possible, as well as to work in a multidisciplinary manner, delving into the latest quality information in order to improve the health care of our patients.
A fundamental point is the doctor-patient relationship and the doctor-family relationship, in order to achieve a global approach to the patient's problems. To this end, it is essential to work on the psychosocial, emotional and spiritual aspects, as well as to provide the necessary and fair information to both the patient and the family members in order to facilitate the assimilation of the process.

Another very influential aspect is the international inequality in terms of recognition of this right and the material and drug availability of the countries. Governments must cooperate and help less wealthy countries to achieve the objectives proposed by the WHO.

CONFLICT OF INTEREST

The authors declare that they have no conflicts of interest.

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