Review / Derleme

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End-of-life care in pediatric palliative care

Pediatrik palyatif bakımda yaşam sonu bakım kavramı

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ABSTRACT

The problem of EOL care of a child is very important because the recovery of a family from grief over a child's death depends on that manner. For improving the quality of this specific care, it would be useful to assess the life expectancy/survival of congenital anomalies, life-threatening diseases, conditions that may shorten a child's life, and the outcomes of palliative care units regarding mortality. Besides, there is an urgent need for more data on what families define as 'good death' and how to cope with the loss. Not only caregivers but also siblings, grandparents, relatives, and healthcare professionals are impacted by a child's death and their needs must be explored. Pediatric palliative care staff in low/middle-income countries need educational assistance for skills of multidisciplinary training about end-of-life care to improve appropriate care for dying children and their families. It is important to provide sensitive and empathetic end-of-life care to children in a family-centered manner helping them to find comfort, meaning, and support while enhancing the quality of a child's life and death. Many attending physicians felt inexperienced when communicating with dying patients and their families while discussing the transition to palliative care and resuscitation status. Also, the good death of a child is an emerging concept in this research domain to improve end-of-life care for dying children and their families. The goal of this review was to provide pediatric healthcare professionals and physicians with an overview of palliative care regarding end-of-life issues.

Keywords: Care, child, end of life, palliative, pediatric

ÖZ

Bir çocuğun yaşam sonu bakımı sorunu çok önemlidir, çünkü bir ailenin ölümle ilgili sıkıntılarından ve kederinden kurtulması tamamen buna bağlıdır. Bu özellikli bakımın kalitesinin iyileştirilmesi için konjenital anomaliler, yaşamı tehdit eden hastalıklar ve yaşamı kısıtlayan durumlarda palyatif bakım birimlerinde beklenen yaşam süresinin ve mortalitenin belirlenmesi yararlı olacaktır. Sadece primer bakım verenler değil, aynı zamanda kardeşler, büyükanne/büyükbabalar, akrabalar ve sağlık profesyonelleri de çocuğun ölümünden etkilenmektedir ve onların ihtiyaçları da önemlidir. Ayrıca günümüzde ailelerin 'güzel ölüm' tabirini nasıl tanımladıkları ve bu kayıpla nasıl başa çıkılacağı konusunda daha fazla veriye ihtiyaç vardır. Gelişmekte olan ülkelerdeki pediatrik palyatif bakım personelinin, ölmekte olan çocuk ve ailelerine uygun bakımı verebilmek için yaşam sonu bakımı hakkında disiplinli bir eğitim almaya ihtiyacı vardır. Bir çocuğun hem yaşam hem de ölüm kalitesini artırırken, bununla birlikte konfor, anlam ve destek bulmalarına yardımcı olan aile merkezli bir yaşam sonu bakım sağlamak önemlidir. Pek çok hekim ve sağlık profeyoneli, ölmekte olan hasta ve aileleriyle iletişim kurarken, canlandırma işlemi ve çocuk palyatif bakıma geçiş noktasında deneyimsiz hissetmektedir. Bir çocuğun başına gelebilecek 'güzel ölüm/saygın ölüm', yaşam sonu bakımı iyileştirmek için ortaya çıkan bir kavramdır. Bu derlemenin amacı, sağlık bakım hizmetleri profesyonellerine ve hekimlere pediyatrik palyatif bakımda yaşam sonu bakım kavramıyla ilgili farkındalık oluşturmak ve daha geniş bir bakış açısı sağlamaktır.

Anahtar Kelimeler: Bakım, çocuk, palyatif, pediatrik, yaşam sonu

INTRODUCTION

Palliative care is a developing pediatric specialty that focuses on the quality of life and symptom management for children who have life-limiting/threatening diseases that have no hope of recovery (1,2). Optimizing and achieving the quality of this care and treating the physical, psychosocial, and spiritual needs of patients and their families is an important healthcare goal (3). There has been a decrease in the children mortality rate, but meanwhile, technological and medical evolution led to an increase in life-limiting and life-threatening diseases. The global under-five mortality rate declined from 93 deaths per 1,000 live births in 1990 to 38 in 2019, by 59 percent.

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Despite this progress, approximately 14,000 under-five deaths occurred every day, in 2019. In addition, chronic conditions like cancer or cardiovascular disease, account for more than 15,000 deaths per year (4). Children who would not have survived their chronic conditions previously are now living longer with very different death courses with medical and technological advancements (5). Pediatric palliative care is defined by The World Health Organization as “aiming to improve the quality of life of patients facing life-threatening illnesses and their families through the prevention and relief of suffering by early identification and treatment of pain and other physical, psychosocial, or spiritual problems.” It begins when the illness is diagnosed and continues until the end of life (6). Therefore, it is important to provide sensitive and empathetic end-of-life care to children in a family-centered manner helping them to find comfort, meaning, and support while enhancing the quality of a child’s life and death (7,8). Many attending physicians felt inexperienced when communicating with dying patients and their families while discussing the transition to palliative care and resuscitation status (9). Besides, the good death of a child is an emerging concept in this research domain to improve end-of-life care for dying children and their families. The goal of this review was to provide pediatric healthcare professionals and physicians with an overview of palliative care regarding end-of-life issues.

Perinatal Palliative Care As An Emerging Speciality

Meanwhile, there is good evidence in the literature that, pediatric palliative care starts during pregnancy (10). Parents may have information from a prenatal ultrasound about their baby’s life-threatening condition and after gathering information they can decide whether to go forward with the pregnancy or not. Perinatal palliative care patients are mainly divided into three clinical groups: (1) extremely premature (<23 gestational weeks) at the limits of viability, (2) diagnosis of life-limiting/threatening diseases with poor prognosis incompatible with life, (3) severe/critical clinical conditions without possible improvement requiring complex care and intensive support (11). After the delivery of the baby, the parents may want to take the baby home if the baby lived (12). In this instance, the perinatal palliative care team provides information and support to parents and family members after postdelivery. As soon as discharged from the hospital, the baby is cared for and loved by family members, neighbors, friends, and the team provides support to the family in terms of arrangements for funeral visits, and spiritual needs. The baby should not experience any pain or distress and should take the last breath in the parents’ arms at home in a few days. Good examples of such an experience are available in the literature (12). Recent medical experience of the healthcare providers offers different strategies for the treatment of perinatal palliative care patients, according to their condition and the diagnosis of life-limiting disease (11). Specific training and collecting dedicated resources are necessary in this regard. To establish proper perinatal palliative care training programs, we must increase the recognition and social awareness of the deficiency of this setting. Clinical, ethical, organizational, and communicational skills can maintain the best interest of the newborn with a life-limiting/life-threatening disease. The collection of shared data and new research is essential in finding novel tools applicable in different centers (11).

Location of Death of a Child

Dying at home may be the choice of many parents, where children die and a child’s location of death may be more important than it is claimed. In a cross-sectional study of 140 parents who lost their child to cancer at tertiary-level pediatric hospitals, it was reported that the chance to plan the location of death was related to outcomes consistent with high-quality palliative care. Most parents were reported to choose a home for the child’s place of death and when non-home deaths were evaluated, parental planning was associated with more deaths occurring in the ward than in the pediatric intensive care unit, and fewer children were intubated. Good communication with physician and home health care services increase the possibility of planning a child’s death location (13). Parental preparedness was also connected with planning the location of death and was a key contributing factor for high-quality EOL care (14). Besides, the parents who planned were more likely to prefer less invasive care at the time of death.

Good Death Concept of a Child

‘Good death’ is a phrase used for persons near the end of life which is not usually used for dying infants and children (12). A child’s death cannot be normalized compared to the death of the elderly, even in nature. Children are considered innocent, and their death raises questions about the meaning of life. Throughout the time in literature, the death of a child led to the questioning of faith in God and harming the belief in the fairness and balance of the universe spiritually (5). Hence, it is a tough question for a person to ask ‘how can the death of a child be good? ‘. It can simply be defined as; a peaceful death that is free of pain and avoidable distress (12). It must accord with patients’ and caregivers’ wishes and their cultural and ethical standards since cultural-specific differences towards dying children are expected. Designing the dying process is required to optimize EOL care for a child. Most of the deaths occur in the PICU with planned withdrawals, but in our country, the order of ‘do not resuscitate’ is not legal, therefore the withdrawal of treatments is forbidden by laws, even when approval of the family exists.

A good death could be identified as being free from distress, dying in a favorite place; having good relationships with family members and medical staff; feeling that life is complete, maintaining dignity, and preparing for death. However, this identification in adult studies, cannot be applied to children completely (14). For the peace of death of a child, environmental regulations of details are important to be fulfilled upon the families' decision (5). Preferred time of day, family members/staff who wants to be present at the time of death, the noise and lighting (alarms must be tolerable), the lines/tubes, machines/monitors, and pumps might be removed for the comfort of the patient. The family may want to perform cultural and religious practices before withdrawing in accordance with their beliefs. Besides, the preferred position of the parents (laying with the child in bed or holding the child in arms), the position of the child in the room (eg, near windows, etc.), and other special requests like playing the child's favorite song or reading the child's much-loved book, ensure the quality of death during his/her last hours (5).

In a comprehensive study, components of a good death for children with cancer were identified as; adequate opportunities to play freely, peer support, continued access to their common activities, assurance of privacy, respect for their decisions and preferences, a sense that others acknowledge and respect their childhood, comfort to minimize distressing symptoms, hope, not being aware of their forthcoming death, constant dignity, strong family relationships, no sense of being a burden to family members and good relationships with medical staff (15). It is necessary to provide a healthy social environment for terminally ill oncology patients such as normal school life with optimal palliative care focusing on patients' physical and psychological distress. Individually tailored care should be provided depending on each patient's age and developmental period to provide high-quality pediatric palliative care (15).

In addition, healthcare workers who are most affected by witnessing and participating in the death of a child, seek good death for their dying patients for improved EOL care since they are an important piece of the support structure. Physicians and healthcare staff are defenseless to the effects of EOL care delivery. Some studies report that providers who have inadequate training and experience in the delivery of this care are vulnerable to feelings of "burnout," insufficiency, and discomfort. Hence, lack of support for staff who provide this care is crucial since it can lead to depression, emotional abandonment, and regression at work (16, 17).

Controversies in Pediatric End-of-Life Care

The prolonged and variable dying process is characteristic of children with chronic conditions complicating their end-of-life care. Medical technology transformed medicine by widening the distinction between death and dying. The death of a child can occur after a few different trajectories. Common four routes encountered in the ICUs are; sudden/unexpected death, death from a lethal congenital anomaly, death from a possibly curable disease, and death from a chronic/terminal disease (5). Therefore, preparation of the family and child for the end of life is necessary to make decisions in their child's interest. As a child proceeds toward death, care goals shift from cure to supportive care and bereavement (5). The honesty and comprehensiveness of information, effect when delivering news, withholding of data, provision of false hope, linguistic complexity (many Syrian refugees are living in our country), speed of providing information, conflicting information, and physician's body language is troublesome communication-related factors which effects the parents' perceptions about adequate care. Parents state that they are "better prepared" with open and honest information because it helped them to know what to expect (5, 18). Moreover, most of the parents want to see the "big picture," and ask for all the information and the truth, no matter what the truth may be (19).

A pediatric survey suggested that concerns about excessively burdensome treatment were greater in pediatric end-of-life care than in adults. Attending physicians were worried 10 times and nurses worried 20 times more across all specialties about "saving children who should not be saved" as about giving up early (20). Physicians like intensivists probably have concerns of conscience about providing excessively burdensome treatments because in neurologically devastated patients restoration to a meaningful existence seems hopeless. On the other hand, hematology/oncology clinicians have concerns of conscience because prognostic uncertainty for pediatric cancer is high and hence cure-oriented interventions are excusable. They usually have longer-term relationships with patients' families and these emotional bonds may weaken their ability to provide objective counseling and advice (20). Pediatric palliative care specialists' thoughts and approaches are probably the same way. Most physicians usually overestimate survival when confronted with an uncertain prognosis. A study has reported that a minimum 3-month gap existed between the time that a physician recognized that the child had no chance of survival and the time that the parents recognized the same (21). Also, there is a belief that families are not ready to recognize an incurable condition besides the fear of anger or blame from parents. In mass media, stories of miraculous recoveries lead people to rely on the endless possibility of medical technology and physicians feel guilty for this, not being certain (22). Families frequently use denial as a coping mechanism and the absence of a consistent and clear message from residents complexes the problem. Using sensitive, caring and honest dialogue between parents and healthcare staff regarding a child's terminal condition assists in the preparation for the dying process (14). Overall, families prepared for death by healthcare workers who were honest, compassionate, and available; feel more comfortable that everything that could have been done for their children was done (5, 23). Hence compassionate and consistent EOL care affects the recovery of a family after a child's death.

The Training About End-of-Life Care

At present, the training in EOL care is not satisfactory in many countries. In a study, 89% of the residents don't feel ready to face EOL management (24). Pediatric palliative care requires specific training, uncharacteristic competencies, and skills along with continuing treatments together with the children and their families for an unpredictable time, probably some years. Children suffer from many symptoms and multiple diseases which require interdisciplinary expertise and in contrast to the stated experience of adult-oriented palliative care services, most children live more than a year after initiating pediatric palliative care (2). Hence, the recent palliative care model supports the administration of curative and supportive treatments simultaneously from a multidisciplinary team that includes nurses, physicians, social workers, child life/ development specialists, pharmacists, dieticians, spiritual care specialists, and physical/occupational therapists (3). Initiative for Pediatric Palliative Care identifies goals for high-quality family-centered pediatric palliative care through six domains. These consist of; 1) communication about treatment goals and plans, 2) ethics and shared decision-making, 3) relief of pain and symptoms, 4) continuity of care, 5) support of the family and, 6) grief/ bereavement support (20,21). With this point of view; key topics for palliative care are communication, pain, physical, psychosocial, spiritual considerations, and ethical/legal concerns (3, 25). The absence of knowledge and skills in this specific expertise area may create hesitation in caring for children. Personal reactions of healthcare professionals include fears and concerns when confronted with death (24).

Declaration of death is also another complex experience. In a tertiary children's hospital study, 44 residents and 52 fellows stated that they desire formal training in three specific areas; which are pain control, delivering bad news, and discussing prognosis (26).

In a study in which pediatric residents were taught how to manage withdrawal or limitation of life-sustaining treatment, how to declare death, complete a death certificate, and have a follow-up with families; it was found that they have limited experience with end-of-life care. Their educational experiences varied and they didn't feel sufficiently trained to perform the responsibilities related to providing EOL care for children. (27). However, in another study, the authors reported that education boosted healthcare professionals' confidence regarding personal knowledge, skills, communication abilities, and ethical/ legal concerns. Besides, providing emotional support to dying children and their families increases after appropriate training (28). Therefore additional and urgent efforts are needed to reach comprehensive and multidisciplinary training for residents of pediatric palliative care and it should regularly be provided with the optimization of a concise and clear methodology. Unfortunately, the awareness of low or middle-income country residents on this issue is not adequate and at the same time, there is a lack of formalized education/ training in the approach and management of end-of-life care. Pediatric university hospitals, children's hospitals, and research hospitals must include their residency programs with a sufficient number of hours devoted to training, not only for pediatric palliative care but also for pediatric EOL care immediately. Therewithal, training courses, conferences, and conventions on these topics may also help to compensate for this deficiency a little bit.

CONCLUSION

The problem of EOL care of a child is very important because the recovery of a family from grief over a child's death depends on that manner. For improving the quality of this specific care, it would be useful to assess the life expectancy/survival of congenital anomalies, life-threatening diseases, conditions that may shorten a child's life, and the outcomes of palliative care units regarding mortality. There is an urgent need for more data on what families define as a good death and how to cope with the loss. Not only caregivers but also siblings, grandparents, relatives, and healthcare professionals are impacted by a child's death and their needs must be explored. Development in the healthcare system must include hospice policies for those with a life expectancy of 6 months or less. Pediatric palliative care staff in low/ middle-income countries need educational assistance for skills of multidisciplinary training about end-of-life care to improve appropriate care for dying children and their families.

ETHICAL DECLARATIONS

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