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Introduction

Palliative care and pediatrics

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Abstract

Palliative care is defined by its Latin root word, palliare, which means "to cloak". Caring for infants whose medical abnormalities prevent a cure involves palliative care with attempts to ameliorate or ease the suffering that this vulnerable patient experiences, because of the medical state, which is present as well as potential effects of modern medical technology. This discussion considers basic principles of such care and emphasizes that it must be conducted by an experienced, professional healthcare team, who are educated in principles of palliation and ethics, who work closely with the parents (family), and keep the best interests of this defenseless patient in mind at all times.

Keywords: Palliative care, end-of-life, neonatal period, pediatrics

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Introduction

Palliative care refers to health care which is “palliative” coming from the Latin word, *palliare* which means “to cloak.” *Pallium* comes from “*palla*”, which was an upper garment worn by females and come from the Proto-Indo-European origin for “*pol*” or “*pel*”, which referred to skin, covering, or pelt. It derives from late Middle English taken from the French “*palliatif*” or medieval Latin “*palliatives*.” It led to the French word “*peau*” or skin and “*poil*” or body hair. This cloaking of something began to take on such synonyms as alleviate, ease, relieve, soothe, allay, mitigate, blunt, and other words of “cloaking.”

Not all babies can be born healthy or whole, but individuals directly involved with infant care can work together to treat, comfort, and ease a seriously ill child
James Strain, MD (1983—Former President and Director, American Academy of Pediatrics)

When applied to health care over the millennia of human history it arose out of a desire to “cloak” or “palliate” the suffering of one with an incurable illness. If one cannot directly treat the cause of the illness nor cure it, at least health care providers could cloak or palliate the individual’s symptoms, particularly the pain that the illness induced. Palliative treatment became a main treatment of illness, since the cause and cure were often unknown.

Human history is full of countless disease epidemics that ravaged the population leading to untold suffering of the ill and dying. Palliative care arose out of the hospice care movement. Hospices were places of rest for travelers in the 4th century and hospices were developed in the 19th century to humanely care for the dying in London and Ireland. Dame Cicely Saunders (1918-2005) established the St Christopher’s Hospice in 1967, which has inspired the modern hospice movement for the dying in current society (1). In addition to caring for the dying patient, the palliative care approach emerged in both caring for adults but also children.

Definition

The World Health Organization (WHO) defines palliative care as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (2).” Palliative care for newborns is a holistic and comprehensive care for an infant whose condition leads his or her caregivers to the poignant conclusion that s/he will not improve (“get better”) and then seeks to cloak or palliate the quality of life for the infant and family (3). It involves a multidisciplinary team seeking to relieve pain and suffering whether the infant is in the hospital, outpatient clinic, or at home.

Baby Doe

Palliative care concepts were stimulated in the United States by the 1982 episode of an infant, “Baby Doe” who was a baby born with Down syndrome in Bloomington, Indiana (4). The parents declined to have surgical repair of the infant’s esophageal atresia with tracheoesophageal fistula and the infant died at 6 days of life on April 15, 1982. The United States Surgeon General at that time was pediatric surgeon C Everett Koop (1916-2013), who argued that the infant was denied surgery because of the Down syndrome status and that surgery would have allowed the infant to have proper nutritional intake to sustain further life.

Another episode occurred in 1983 with a newborn called “Baby Jane Doe” in Port Jefferson, Long Island, United States whose parents refused life-sustaining surgery for their newborn with meningomyelocele, hydrocephaly and microcephaly (5). A lawsuit ensued as well as evaluation by the US Department of Health and Human Services and the New York Child Protective Services. The US Surgeon General again weighed in on this situation recommending surgery for this infant and concluded surgery should not be withheld, because of the infant’s medical situation was complicated by mental disability.

The impact of these and other cases along with the encouragement of the US Surgeon General lead the US Congress to pass the Baby Doe Amendment and it became law on June 1, 1985 as an amendment to the Child Abuse Law; it defined withholding of medically indicated treatment, fluids, and food from disabled children as being child abuse (6). The regulations involving Baby Doe Hotlines were struck down by the US Supreme Court in 1986.

However, these cases led to a national debate on the extent of care deemed necessary or humane for disabled infants, an issue that has been debated over the millennia of human history (7). As noted by a former president and medical director of the American Academy of Pediatrics in 1983—James Strain, MD: “Not all babies can be born healthy or whole, but individuals directly involved with infant care can work together to treat, comfort, and ease a seriously ill child” (8).

In 1988 US Federal provisions called “Baby Doe Rules” emerged from US Congressional review and dealt with issues involving “withholding of medically indicated treatment” in infants (9). This was part of the 1988 Revision of the Child Abuse Prevention and Treatment Act (CAPTA) and required that all infants be given “appropriate nutrition, hydration, and medication” unless “the infant is chronically and irreversibly comatose, provision would merely prolong dying, and provision of such treatment would be virtually futile in terms of survival...(9).” Such rules were to be applied even if parents wish to stop such measures. Congress passed the Born-Alive Infants Protection Act (BAIPA) in 2002, which has increased discussion on caring for the extremely premature infant (10).

These rules continue to be in debate in current American society and some raise the concept that parents should be able to weigh in on such life-sustaining principles and that parents should be able to decide such issues about their child even if others disagree (11,12). The American Academy of Pediatrics (AAP) concludes that day-to-day treatment measures should be decided by the infant’s parents and caretakers (13). The AAP also recommends that care for infants with a “very poor prognosis” involve appropriate communication between providers and parents regarding the medical condition, prognosis, and treatment options; palliative (“comfort”) care is recommended that is in the best interest of the patient even if intensive care is withdrawn (13).

The close involvement of parents in such care is also supported by the American Medical Association which notes: "In caring for defective infants the advice and judgment of the physician should be readily available, but the decision as to whether or not to treat a severely defective infant and exert maximal efforts to sustain life should be the choice of the parents" (14). In cases of dispute between parents and others, hospitals typically have ethics committees to provide further guidance. As noted by White, there have been few legal challenges using the Baby Doe rule to wishes of parents in caring for their disabled infant and no state has lost Federal funds for failing to follow CAPTA rules (9).

Palliative care for newborns

Cloaking the severely ill or disabled newborn is a task that requires cooperation of the parents and a multidisciplinary group of hospital and outpatient personnel. The newborn usually comes from a family and the AAP supports the role of "family pediatrics" in the care of children of all ages (15). In this approach, perspectives of the parents must always be kept in mind as decisions about intensive care and palliative care of the newborn are formulated (16).

The movement of palliative care has grown to a considerable extent in hospitals and often specialists in palliative care can be found on the hospital staff who can provide education to hospital personnel in this field (including novices) and help establish pediatric palliative care programs (3,17-24). Children Hospital's personnel involved in the care of the newborn patient must be educated in the hospital's palliative protocol. The role of culture and spirituality in the family should always be respected, understood, and incorporated into mutual decision-making (25-29). Palliative care protocols for newborns are found in different countries that may have differing views on exact principles of newborn palliation (30-33).

As difficult as it is, palliative care for the newborn seeks to cloak this patient keeping the patient's best interests in mind as much as possible (34,35). Careful attention should be paid to the level of noise (i.e., limited) and light (i.e., soft) that envelops the newborn. Palliative care can include the ongoing use of medication such as anti-convulsants and anti-pyretics.

Pain and the neonate

Pain is an important issue for all patients and as the science of understanding pain in the newborn augments, principles should be applied to cloak this vulnerable patient with as minimal pain as possible utilizing accepted pain scales (i.e., CHIPPS: Children's and Infants Postoperative Pain Scale, Premature Infant Pain Profile, FLACC [Face Leg Activity Cry Consolability], others) and analgesics as well as on-going healthcare education in neonatal pain management (36-42).

Pain afferent tracts develop at 21 weeks of gestation and the fetus has mature pain receptor mechanism after 26 to 30 weeks (43,44). Scales seeking to measure neonatal pain have been developed based on vital sign changes (i.e., blood pressure, pulse, respirations), oxygen saturation changes, facial expression, crying characteristics, sleep alterations, body/extremities' movement, and others (44).

Adults typically and historically underestimate and thus, under-treat the pain that a newborn may be in and this limitation should be avoided, while better methods of pain assessment are identified (45-48). It was concluded over the centuries that newborns did not feel pain and only in the recent past have attempts been made to ease or cloak newborn pain as well as understand that newborns react to pain even more than adults (48). Chronic pain in neonates remains poorly understood and can lead to alteration of pain perception (49).

Avoidance of unnecessary procedures that induce pain is recommended (50,51). Non-pharmacologic measures for pain relief are utilized such as therapeutic touch, facilitated tucking, swaddling, Kangaroo care, breastfeeding, and white noise (52-55).

The use of oral sweet-tasting substances (mostly sucrose) has been studied intensely as an effective pain intervention in newborns by inducing calming and analgesic effects (56-58). However, more research is needed on effects of repeat sucrose administrations with other measures (i.e., Kangaroo care or analgesics) as well as more research on the effects of oral sucrose in very low birth weight neonates or neonates on ventilators (59).

Various topical anesthetic creams and subcutaneous analgesia are utilized in addition to regional anesthesia. Attention to the details of the procedures can relieve pain such as giving injections or taking heel sticks only with close attention to the type of needle used, the injection technique, and addition of pain control measures (60).

Non-pharmacologic techniques have their limits in pain control and more severe pain requires use of paracetamol (acetaminophen: 60 mg/kg/day in term neonates), non-steroidal anti-inflammatory drugs (NSAIDs), and opiates (i.e., morphine and fentanyl in the hospital setting; codeine if in a home setting) (61-65). Research is evaluating use of intravenous paracetamol and other pain-relieving drugs such as remifentanyl, tramadol, and benzodiazepines (i.e., midazolam, others) (66,67). Side effects of these and other drugs on the newborn and premature infant must always be considered and close monitoring is needed. It is important to understand drug metabolism in neonates and how it differs from older children and adults. Attention to the delivery of the drug can be important, as seen with oral drugs, suppositories, buccal delivery, intravenous administration, or intranasal delivery.

Palliative milieu

Health care providers must remember that palliative care can be provided in various settings, including the hospital, hospice care center, outpatient clinic, and the home. Appropriate transportation issues must be arranged from transfer to the tertiary care hospital and then if necessary, back to the patient's community (local hospital or home).

An appropriately sized "palliation" room is recommended for the newborn that can deal with the family, clergy, and other staff personnel. Translation services should be available as needed on a 24 hour basis. Simple language is utilized in discussing issues with the family and this has been outlined in a 1999 American Medical Association training publication (68). The parents and family must understand that the healthcare team will not abandon them in this critical time. They also will benefit from well designed hand-outs printed in simple language that provide useful information about procedures, genetic testing, transfer options, end-of-life protocols, and follow-up options with social worker or clergy. Proper language

must be agreed upon on by staff such as not using the phrase “end of life” and other provocative or frightening words or phrases.

Education of parents to deal with modern technology (i.e., tracheostomies with assisted ventilation, gastrostomies for nutrition) is important to allow parents to care their disabled newborn as parents and healthcare providers work together to provide palliative care requested by parents (69). Many parents find it helpful to discuss palliative issues with other parents who are or have been in similar situations. All parents find this situation stressful and potentially overwhelming regarding of culture, education, or religion.

End-of-life

Discussion of withdrawal of ventilators is a delicate process and should be done with utmost professionalism. Neuromuscular blocking agents (paralytics) should be stopped hours before ventilator withdrawal to avoid having rare effects of these medications be interpreted by family members as causing the newborn’s death (17).

End-of-life issues complicate palliative care measures in the complicated path of going from intensive care to palliative care to care for the dying newborn. Having an experienced and trained health care group who remain in close communication with the newborn’s parents (family) and keeping the infant in comprehensive palliative care are critical in such a potentially overwhelming situation (70-72). It involves keeping the best interests of the newborn patient in mind as well as the understanding the wishes of the parents. Some differences in protocol can be expected from country to county in such a delicate and ethically-charged process (32). Use of palliative care teams in the process is important for the hospital staff, the family, and the patient (73).

Transitions of care from curative to palliative to end-of-life is not about physiology so much as it is about the individual newborn, the involved family, and the professional healthcare providers who are involved (74). Close and constant communication between the responsible staff and family is always critical in all cultures and countries (75-77). It is often a difficult, highly emotional, poignant, and controversially-charged principle to always keep the best interests of the infant in mind while balancing the views of parents and hospital staff (12,78-84). Frequent meetings of the staff are helpful to deal with these intense issues and post-discharge de-briefing sessions are also beneficial to help staff members deal with the impending and actual death of their patient.

Doctors prescribe medicine of which they know little, to cure diseases of which they know less, in human beings of which they know nothing."
Francois Voltaire (François-Marie Arouet 1694-1778)

Summary

For parents around the globe the joy of having and raising their child (children) is inexpressible and remains one of life’s greatest challenges as well as rewards. Having a newborn who requires palliative care is an ethical, emotional, and exhausting experience.

Seeking to cloak or ameliorate the newborn's suffering requires close communication between the parents and an experienced hospital or outpatient staff who are educated in modern principles of palliation science. Principles of a neonatal end-of-life palliative care protocol have been well outlined by Catlin and Carter (17).

The transition from intensive care management to palliative care is vital for all concerned and the heart of the issue is for the professional healthcare team to keep the best interests of the newborn patient in mind at all times. The healthcare team must remain persistently professional and the basis of medical professionalism is to place the needs of one's patient above one's own needs or interests.

Professionalism is the habitual and judicious use of communicating knowledge, technical skills, clinical reasoning, emotions, values and reflections in daily practice for the benefit of the individuals and community being served (85)

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