Review Article

Fetal and Newborn Palliative Care in Islam-When to be Considered: A Review

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Abstract

Background: Palliative care is specialized, individualized medical care to comfort people with terminal or life-threatening diseases. The article provides an overview of proper palliative care and challenges faced by the health care system during treatment of Muslim neonates. Discussion: It is seen that most of the neonatal intensive care units (NICUs) in Middle East have not yet adopted structured programs related to neonatal palliative care. The reason behind this is suspected to be lack of awareness and adequate knowledge of the programs. There might additionally be a fear of being accused as being stone hearted by not providing invasive intensive care to babies who are critical. Novel questions posed by medical advances such as those related to fetal and newborn palliative care requires a degree of interpretation and application of the Quran by authoritative teachers (Imams). This has led to diverse inferences and continues to be an extremely challenging topic needing awareness and sensitivity on the side of fetal and newborn care providers. Summary: This is a debate on the importance of educating the caregivers and care taking units for providing palliative care for neonates.

Keywords: Neonatal palliative care, neonatal intensive care units, palliative care for neonates in Middle East

Introduction

The World Health Organization (WHO) defines palliative care as the primary goal for the provision of a good quality of life for those with life-threatening diseases. The definition further explains palliative care for children and neonates as a special field that includes care of the neonate's family. The WHO has set up principles of palliative care for children and includes the following points:

a) Complete care of the infant must be taken including mind, soul, and body

b) Moral support to the family should be provided

c) Palliative care should start when the decision for not providing any more intensive care has been made

d) Care should be implemented even when resources are limited [1].

Most deaths in the pediatric population occur during the neonatal phase and due to infections [2]. In US, congenital anomalies, account for approximately 24% of neonatal deaths followed by low birth weight, small for
gestation age, placental complications, and heart diseases [3]. A single center report generated in Saudi Arabia stated that 79871 live births were recorded, and 526 deaths presented with preterm birth and its complications, i.e. 42% neonatal and postnatal deaths occurred due to such prematurity. Lethal malformations (36%) were the next commonest cause, followed by 17% of cases died due to other causes while hypoxic ischemic encephalopathy accounted for 5% [4].

As per the reports from the Institute of Medicine in the U.S, 34% of childhood deaths occur in the early infant stage [5]. A survey of 193 countries reported the leading cause of neonatal deaths to be infections accounting for 35% of deaths [6]. The next in the row is preterm birth accounting for 28% of deaths and asphyxia causing 23% deaths [7]. In the Saudi Arabia region, the scenario is quite different. Thus, neonatal palliative care should consider the following points. First, there are no proper limits set regarding neonate viability i.e. the capacity of the fetus to survive in the surroundings outside of uterus. It is the responsibility of the healthcare community to maintain viability as science and technology advance and define limits for the same [8]. Second, when there is a confirmed diagnosis of a life-threatening abnormality in the fetus, the parents of the unborn child should not be deprived of medical treatment for the unborn. Third, when the neonate has failed responding to medical treatment; the decision to continue the treatment and prolonging his suffering need to be comprehensively addressed [8]. The decision of continuing therapy with aggressive interventions versus withdrawing is the most challenging decision in pediatric medical practice [5].

Davies in 2008 conducted a survey which showed that almost 40% of healthcare professionals said that cultural differences acted as barriers to proper palliative care. Among ethnic minorities, specifically Latino, Indian, Native and African-Americans, the facilities of palliative care are not properly utilized. The reasons which prevented the families from taking palliative care could be lack of familiarity with hospital in-patient and out-patient services as well as the palliative care services offered by the health care system. Other reasons can be language barriers, religious differences, distrust for the healthcare providers, having discomfort with introducing additional services and hospice activities with professionals not of one’s ethnic or cultural background into the home, discomfort of the doctors, or a combination of factors [9,10]. Comprehensive ethical codes conforming to Islamic and legal standards are required to aid decision making.

Inconsistency and incomplete reporting of newborn death is common in children needing palliative care. This could be explained by the fact that many infants die at home and are not reported as they die due to lack of healthcare services and no palliative homecare [2].

Palliative care is also continuum of care. It has been observed that the current healthcare system lacks continuity in treatment during the end stages, especially when it is certain that death is the only outcome. Even if a neonate is dying, care should be taken to minimize suffering. Treatment alternatives should be included in the existing management as a comprehensive approach to palliative care. Effective communication is required between healthcare providers and the decision making individuals of the patient’s family. Family members should have a clear idea of the health condition of the child. Awareness programs can be conducted to emphasize the need of palliative care. Nurses, who have experience in palliative care, administrators, neonatologists, and other skilled professionals should participate in these programs [11,12].

**Muslims and Palliative Care**

Muslim patients need care. However, the method of taking their care of requires meeting their needs which do not hinder or disrespect their culture and beliefs. Islam and Quran provide guidance in spiritual matters. It also has considerable emphasis on health and prevention. Islamic beliefs generally affect Muslim patients’ way of thinking
as well as their perception and behaviour in hospital and community settings. Therefore, it is essential for the health care providers to understand the Islamic culture and their beliefs to offer care which is culturally appropriate and acceptable. The cure comes solely from Allah is what Muslims believe and health care professionals are a medium of delivering the cure. In addition, while taking care of a Muslim patient, understanding of certain acts and their impact on compliance to treatment is essential as this may lead to positive and negative outcomes, respectively [13].

The word “Islam” means peace and submission to the will of Allah (translated literally as “the God”). Prophet Muhammad is considered by Muslims as an exemplar and role model. They follow Quranic instructions and try to emulate everything in their own lives with the life of Prophet Mohammad. The teachings in the holy book of Muslims have influenced medicinal practices and various aspects of life like birth, death, and illness. These aspects make provision of healthcare for Muslim patients trickier than other religions. The beliefs tend towards following the content of their holy books, rather than seeking assistance from health care system [14]. A cross sectional survey identified and formulated recommendations regarding challenges faced by the health care system while considering redirection of care (ROC) for Muslim neonates. It was reported that out of 198 respondents, 36.7% did not recommend ROC (reasons: prognosis uncertainty, ethical issues, fear of legal repercussions) whereas, 63.2% favoured ROC. The study demonstrated socio-cultural and religious barriers of Muslims in undertaking palliative care [15].

Islamic tradition still follows the rule of “balance and imbalance of humours in the body from the Humoral Theory” as the difference between health and illness. According to them, Quran is a healing source when they are in psychological and spiritual distress. Moreover, Muslims believe in avoiding taking the help of palliative care system. Even if the patients need a surgical or medical curative process, they often seek some other approach of healing that includes visits to their religious and cultural heritage places to address spiritual, social, and cultural needs beyond conventional medicine [16]. However, in case of physical illness, Muslims are open to rituals and medicinal practices followed by other traditions, including those of non-Muslims [14].

Discussion

Standards of palliative care

Australia has published the Standards for Providing Quality Palliative Care in 2005. The new born infants receive these standards of palliative care. They are being provided with proper care, decision making, and planning. Each of these cares, decision making, and planning is based with respect to the uniqueness of the patient and family. The needs of the neonate and their family’s needs and sentiments are heard and accordingly guidance and decision making are considered. To minimize the burden on the family, they are told the truth. The family is provided with information, support, and guidance according to their needs and wishes. The individual requirements of the patients should be considered, maximizing comfort. Palliative care must be available to all infants irrespective of cultural background, sentiments, or the place where the child belongs. Palliative care staff should be well trained and qualified for providing quality services. Palliative care has its own philosophy, motives, and values. Palliative care needs time-to-time revision to maintain effective strategies in the constantly changing face of healthcare [1].

Aborting the fetus: is the fetus considered alive?

Muslim societies have specific beliefs and practices with regard to reproductive rights, social beliefs and values. An understanding of these is essential to understand their abortion criteria. After the interpretations of their religious book, several laws have been set regarding abortion.

The Islamic World League in its 12th session in 1990 passed a Fatwa stating that abortion would be allowed if the fetus was malformed and some threatened disease might affect the child and is untreatable. Islamic
Jurisprudence Council of Makkah agreed to it. However, the disease must be proved by a series of investigations by trusted physicians, and it should take place within 19 weeks of gestation i.e. 120 days.

On request, early abortion can be done in some countries such as Tunisia, whereas five other countries (Algeria, Egypt, Iran, Pakistan and Turkey) give permission to abort if the mother’s health is seriously affected by the presence of fetus. Many countries permit abortion in the case of rape or serious fetal abnormalities. In most of the Muslim countries, safe abortion is limited due to the restricted access to medical and social services [17].

Muslim law universally accepts that abortion be permitted if continuing the pregnancy would have serious impact on the mother’s life. After 19 weeks of gestation, Muslim law accepts maternal health issue as the only reason. The Quran clearly mentions that a fetus must not be killed because of the fear of being poor or the fear of not being able to look after the baby after birth. The Quran mentions that people should have faith and trust in Allah to look after things: “Kill not your offspring for fear of poverty; it is we who provide for them and for you. Surely, killing them is a great sin.” Quran 17:32.

Of late, in Saudi Arabia, the General Presidency of Scholarly Research and Ifta issued a legal opinion (Fatwa no. 231, March 6, 2008) regarding preterm babies born at less than 6 lunar months’ that is 25 weeks of gestation and 2 days. The legal opinion clearly stated that: “In the case of infants born at less than 6 lunar months, two specialist physicians could study the infant’s clinical condition, and based on their opinion, the infant could be offered full resuscitation if it is beneficial to the infant or he or she can be left without intervention to die but should not be deprived of nutrition or fluid.”

The sole decision maker according to this fatwa is the physician who is treating the child. It is the responsibility of the physician to know about the risks to the child, and he should be knowledgeable and trained enough to make such critical decisions.

Various factors come into play in such situations e.g. geographical location and the amenities available. It can be extremely difficult to make such a critical decision in the confines of the delivery rooms with minimal time. Delay in taking such decisions may adversely affect the infant’s health. Hypoxia and neurological stress may get aggravated. However, there are no laws for the treating physician, and he can discuss it with the pediatricians and caregivers. This law is encouraging for the Islamic society. It will help to establish guidelines throughout the Islamic society. Steps of the law process are as follows [10,18]:

1. Confirmation of lethal malformations by ultrasonography and/or chromosomal analysis
2. Approval of the malformation by at least two experts in neonatology and perinatology
3. Documentation of type of malformation in medical records of the mother
4. Obtaining a written consent from parents or their delegates
5. Abortion is allowed, in case the gestational age is more than 19 weeks, only if the continuation of pregnancy is expected to result in the death of the mother.
6. In case the gestational age is 19 weeks of gestation or less, abortion is allowed only if there is an expectation of child’s death after delivery, or in case of incurable deformity of the fetus
7. If fetal death is medically confirmed in the womb of the mother, abortion can be performed at any stage of pregnancy
8. Provision of palliative care for alive newborns with lethal malformations
### Barriers in the path of neonatal palliative care

The provisions for palliative care remain ad hoc, although protocols are available for palliative care to the suffering children and families. There are several barriers due to which adequate palliative care cannot reach the needy. Lack of staff members that can support these palliative care programs remains one of the major barriers. Inappropriate infrastructure and lack of technologies is the second major drawback. Lack of communication between healthcare providers and the family also affect the decision making process.

Palliative care body Neonatal Palliative Care Attitude Scale (NPCAS) surveyed and found the following key barriers: (a) death of a baby being viewed as a failure; (b) adjustment from a curative to palliative care approach; (c) communication difficulties with the parents of suffering neonates; (d) previous and traumatic exposure to neonatal death; (e) conflicts of decision amidst providers regarding end-of-life; (f) NICU environment; (g) nurses providing palliative care are not being supported; and (h) lack of proper training to the nurses [19].

Muslims even today do not prefer dying in hospitals and people with terminal illness stay at home with their families until they die. Another point of concern is regarding using morphine which Muslims do not consider as a treatment option. Many Muslim families do not like to be reminded of their child’s illness again and again. They believe more on God then on medicines. They believe God’s medical science has power to cure ailments. Some are also against on donating organs. Most of them go for hospice care if at all they agree for treatment but still do not accept going to hospital [20].

Decision making is the most important concern surrounding neonatal palliative care. When should limitations of lifesaving interventions be taken into account and when not? Newborns needing palliative care can be categorized as the following and decision should be taken based on the category.

- **“Beneficial”**- where the lifesaving drug can be used, and the outcome is positive and beneficial.
- **“Futile”**- where using the lifesaving drugs might not have the desirable outcome and the interventions are not accepted.
- **“Grey zone”**- results of the therapy should be able to justify the use of the lifesaving drugs [20,21].

The physicians who are concerned with the palliative care should decide whether to opt for treatment based on the judgment of the possible outcomes. It also depends on the parents’ decision as to what parents want. The doctor should inform correctly about the health of the patient. There should be proper communication between doctor and guardians [21,22].

It is evident in the WILST survey that parents are more optimistic than the healthcare providers. They generally ignore and neglect the health condition of the neonates. How the dying neonates be treated, and their families be consoled is a major concern. Previously, the dying children were kept hidden from their parents to reduce the mourning. Now the case is not the same. Parents are informed about the child’s condition [23].

Prenatal ultrasound for screening the fetus during pregnancy has become widespread. Obstetricians in American College of Obstetrics and Gynecology, 2009; American Institute of Ultrasound in Medicine, 2013 recommend a mid-trimester screening ultrasound for all pregnant women. Parents also eagerly wait for the ultrasound image and consider it as a part of the pregnancy experience. According to Lalor and Begley, in 2006, the attachment increases with the fetus. Also, the anxiety and stress are reduced by seeing the baby on an ultrasound [24].

In 2% cases, where dangerous fetal abnormalities are found, the practice of ultrasound imaging turns out to be traumatic and depressing for parents knowing about the fatal condition of their child [25].

Healthcare providers are finding it difficult to provide adequate and appropriate care because of the growing differences in culture, beliefs, and value systems. The life of an infant depends on how we care for them and ensure
minimal suffering along with best quality of life. The aim is not solely curative, but the therapy should also be humane. For some guardians, palliative services have no meaning and they consider them unnatural. There are a lot of treatment discrepancies between doctors and parents and lack of understanding about palliative care leads to delay in treatment and may increase the physical discomfort for the child. A study conducted in 2008 states that around 40% of the healthcare professionals found that cultural and religious differences are the biggest barrier in palliative care [26,27].

**The role of culture in decision making**

Cultural norms differ between families. These are important as it influences decision making. In some cases, the decision is not only of the family but also it extends people in the community and relative’s [28]. A study reports that few families depend on the community leaders who can help in decision making. Some cultures practice independent decision making and do not believe in controlling the lives of others. However, some cultures pose restrictions, which can affect decisions. Gender, in most families, plays a typical role in decision making, especially in Asian and Latin cultures. Decision making is not given in the hands of the female as she is only considered to be the caretaker of the family [10,29].

**Steps to be taken**

Healthcare professionals need the support of the palliative care team, their colleagues, and institutions and must be supported by the same to deal with the process of child’s death. Institutions may also support by providing paid leave on funeral. They may get the routine counselling done by a trained peer or psychologist along with conducting and remembrance ceremonies regularly. Other interventions may also help such as inviting bereaved families for celebrating the deceased child’s life with staff. Barriers which hinder the families to take benefits of pediatric palliative care services are generally the financial, and educational constraints. Professional and public education may improve awareness of the families in terms of the need for and value of pediatric palliative care. This may lead to removal of bureaucratic and economic obstacles. Continued Improvement of Pediatric Palliative Care through Research and Education Clinical research concerning the effectiveness and benefits of pediatric palliative care interventions and models of service provision should be promoted. In addition, already available information regarding pediatric palliative care must be effectively disseminated and incorporated into education and practice [2,8].

**Conclusion**

Though the palliative care is new era of medicine, it efficiently manages to transform end of life care, but the Muslims have not availed these facilities in proportion to their numbers [30].

Limited resources and cultural restrictions in the areas of neonate palliative care are the factors that are hindering the development of palliative care services in the Islamic world. Healthcare professionals need to understand the religious and cultural aspects of the community in order to provide better care. It requires more commitment from a doctor to understand the needs of a Muslim patient as they have many dos and don’ts in their culture. Some notions such as euthanasia are strictly prohibited in Islamic society.

The culturally rooted bright families can support the society and encourage for availing the hospice and palliative care. It is difficult to predict the future of palliative care in Islamic society. Programs are being conducted worldwide to promote palliative care; still it is underdeveloped in Islamic culture. This remains the point of concern.

**References**
