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Mini Review Open Access

An Islamic Legal Perspective on the Status of the Malformed Fetus and the Previable Infant

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Abstract

Congenital anomalies contribute a significant proportion of infant morbidity and mortality, as well as fetal mortality. To date, there are more than 4,000 known birth defects. Antenatal diagnosis through recent advances in ultrasound and prenatal testing is important to make an informed decision of whether to continue or interrupt a pregnancy. Studies in Europe and North America show that termination rates following antenatal diagnosis of a malformation are common across these countries. Late termination of pregnancy for fetal abnormality is permitted on differing grounds in different countries, depending on the type of malformation, gestational age at diagnosis and abortion legislation. The decision to terminate an affected fetus may be influenced by a variety of factors, such as the country's laws and health system, as well as the parental level of education, socioeconomic status, and religious and cultural beliefs.

Advances in the technological and clinical care of preterm infants have led to improved survival rates for extremely low birth weight infants, but significant morbidity and disability persist. Physicians and parents have to make difficult decisions, often within a short time of birth, about whether to resuscitate and give intensive care to neonates born at ≤25 weeks' gestational age. The decision to remove life-sustaining care from a critically ill baby is difficult and often distressing for parents and health care providers. This mini-review considers religious and ethical aspects of such decisions in the context of Islamic law.

Keywords: Infants; Malformation; Abortion; Anomalies; Limit of viability; Pre-viability; Congenital

Introduction

Congenital anomalies contribute a significant proportion of infant morbidity and mortality, as well as fetal mortality. A congenital anomaly is defined as an abnormality of structure, function or body metabolism that is present at birth (even if not diagnosed until later in life) and results in physical or mental disability, or is fatal. They are generally grouped into three major categories: structural/metabolic, congenital infections, and other conditions [1]. Although no specific definition for lethal anomaly exists, most practitioners use it to refer to an infant with severe neurological compromise and structural anomalies that, if untreated, would cause death within a few months. Examples are Trisomy 13, Trisomy 18, and anencephaly. Advances in medical technology and the introduction of routine prenatal screening allow the diagnosis of various fetal malformations throughout pregnancy. To date, there are more than 4,000 known birth defects [1].

Although making the diagnosis antenatally through recent advances in ultrasound and prenatal testing is important; providing information to make an informed decision of whether to continue or interrupt a pregnancy is quite crucial [2].

Studies in Europe and North America show that termination rates following antenatal diagnosis of a malformation are common across these countries [3]. A review of 20 studies found overall termination rates of 92% for Down's syndrome, 64% for spina bifida, 84% for anencephaly, 72% for Turner syndrome, and 58% for Klinefelter syndrome [4]. Forty-five per cent of the world's countries permit abortion for fetal impairment, including 32% and 84% of developing and developed countries respectively [5]. Moreover, late termination of pregnancy for fetal abnormality is permitted on differing grounds in different countries, depending on the type of malformation, gestational age at diagnosis and abortion legislation [3,5]. The decision to terminate an affected fetus may be influenced by a variety of factors, such as the country's laws and health system, as well as the parental level of education, socioeconomic status, and religious and cultural beliefs.

The severity of structural anomalies directly correlated with abortion rates of anomalous fetuses. Furthermore, at similar degrees of severity, central nervous system anomalies were more likely to be terminated electively [6].

In terms of previable infants, advances in the technological and clinical care of preterm infants have led to improved survival rates for extremely low birth weight infants, but significant morbidity and disability persist. Physicians and parents have to make difficult decisions, often within a short time of birth, about whether to resuscitate and give intensive care to neonates born at ≤25 weeks' gestational age. The decision to remove life-sustaining care from a critically ill baby is difficult and often distressing for parents and health care providers. This paper considers religious and ethical aspects of such decisions in the context of Islamic law. Relevant verses from the Holy Quran are reviewed, as well as a fatwa issued in Saudi Arabia in 2008. These offer guidance on end-of-life decisions for premature infants born at less than at ≤25 weeks' gestational age. The fatwa indicates that decisions can be based on the opinion of two specialist physicians who have studied the infant's clinical condition. If full resuscitation is not considered beneficial to the infant, intervention need not be offered and the infant could be allowed to die but he or she should not be deprived of nutrition and fluid. This legal opinion is in accordance with the general view among pediatricians and other professional caregivers. The fatwa could be regarded as the first step in encouraging Islamic leaders to discuss this important topic with consultant pediatricians to establish guidelines for practicing physicians to follow throughout the

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Islamic world.

In this mini-review, we discuss the current debate regarding aborting a malformed fetus in Saudi Arabia with a focus on the Islamic perspective.

Is a Fetus a Human Being?

Many of the debates turn on the status of the fetus, as if would like to a fetus is a person?, and does a fetus have moral or legal rights? The simplest definition of a person may be "a member of the species homo sapiens, the human species" [7].

Those who consider the fetus is not a person may allow terminating its life and might extend this definition to the newborn infant immediately after birth because the fetus before birth and the infant after birth are the same individual. Therefore, killing the fetus is killing an individual human being.

Others see the concept of a person does not suffice to settle the abortion issue, for the biological development of a human being is gradual. Jane English stated in one of her article [8] that whether a fetus is a person or not, abortion is justifiable early in pregnancy to avoid modest harms and seldom justifiable late in pregnancy except to avoid significant injury or death. She gave long and serious arguments for these positions.

Furthermore, is the abortion of a malformed fetus permissible or not? On one hand, we may want to insist that women carry malformed fetuses to term, because the danger to the woman is not present, and this is the only justification for abortion. However, there is another way of looking at this. Since abortion is not absolutely immoral as is infanticide, we can say that agreeing to carry a malformed fetus to term is also immoral, as since it is very expensive to raise a malformed child, society will pick up the tab. It is immoral for a person to act in ways that result in compelling society to help financially. It is immoral to accept charity if we have the opportunity to work and so avoid accepting charity. It is noble to give charity, but it is immoral to ignore reality and become dependent upon charity. In the case of the malformed fetus, we need to look at the broad picture and decide. Again, this is not the case for infanticide, which is immoral, with no mitigating circumstances.

The wide variety of laws throughout the world was written specifically to protect born human beings and their property. There is virtually no legal precedent for applying such laws to fetuses [9]. Even when abortion was illegal, it had a lesser punishment than for murder, and was often just a misdemeanor.

Fetuses are uniquely different from born human beings in major ways, which casts doubt on the claim that they can be classified as human beings. The most fundamental difference is that a fetus is totally dependent on a woman's body to survive. Some might argue that born human beings can be entirely dependent on other people too. Moreover, anybody can take care of a newborn infant as any disabled person,but only that pregnant woman can nurture her fetus.

The beneficence-based obligations to the fetus exist when the fetus is reliably expected later to become a child and subsequently to achieve independent moral status [10]. We therefore abandon these futile attempts to understand the fetus as a person in terms of independent moral status of the fetus and it can be presented for medical interventions, whether diagnostic or therapeutic, that reasonably can be expected to result in a greater balance of benefits over harms for the child or person the fetus can later become.

Aborting a Malformed Fetus

An understanding of variations in Muslim beliefs and practices, and the interplay between politics, religion, history and reproductive rights is the key to understanding abortion in different Muslim societies. Important efforts, including progressive interpretations of Islam, have resulted in laws allowing for early abortion on request in two countries; six others permit abortion on health grounds and three more also allow abortion in cases of rape or fetal impairment. However, medical and social factors limit access to safe abortion services in almost all the Muslim countries [11].

All schools of Muslim law accept that abortion is permitted if continuing the pregnancy would put the mother's life in real danger. This is the only reason accepted for abortion after 19 weeks of gestation. The Qur'an makes it clear that a fetus must not be aborted because the family fears that they will not be able to provide for it - they should trust 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." Qur'an 17:32.

Widely quoted is a resolution of the Islamic jurisprudence council of Mekkah (the Islamic World League) passing a Fatwa in its 12th session held in February 1990. This allowed abortion if the fetus was: grossly malformed with untreatable severe condition (Table 1) proved by medical investigations and decided upon by a committee formed by competent trustworthy physicians, and provided that abortion is requested by the parents and the fetus is less than 120 days (19 weeks of gestation) computed from moment of conception.

In Saudi Arabia, efforts to legalize abortion in certain circumstances have been recently discussed among Senior Religious Scholars and specialized physicians to permit abortions in certain circumstances. The Council of Senior Scholars issued a legal opinion (Fatwa-240) on this subject on 16 January 2011, and based on the two verses from the Holy Quran: (But whoever is forced [by necessity], neither desiring [it] nor transgressing [its limit], there is no sin upon him. Indeed, Allah is Forgiving and Merciful). (Al-Baqara-173) and (He has chosen you and has not placed upon you in the religion any difficulty) (Al-Hajj-78), The legal opinion came up with the following items:

1. It is permissible to abort a malformed fetus after 120 days of conception (19 weeks of gestation) (when the soul joins its body) if the continuation of pregnancy is expected to result in the death of its mother
2. It is permissible to abort a malformed fetus before 120 days of conception, if its death is expected following delivery, or if the fetus has severe disabilities that cannot be cured
3. The fetus can be aborted at any stage of pregnancy, if its death is medically confirmed in the womb of its mother
4. In all circumstance, it is not permissible to abort a fetus without a medical report from a specialized and trustworthy committee that is composed of at least three physicians, after obtaining a written consent from parents or the mother alone if the continuation of pregnancy is affecting her health. The consent can be obtained by the delegates of parents, if they cannot give it for any reason. The signed consent must be kept in the medical record of the mother.

Limit of Viability and the Islamic Legal Opinion

Survival of preterm neonates of ≤25 weeks' gestational age has steadily improved over the past decades [12,13]. Advances in our understanding of fetal, transitional and neonatal physiology and

- Severe hypoplastic left heart syndrome
- Pentalogy of Cantrell
- Osteogenesisimperfecta type II
- Lethal form of hypophosphatasia
- Thanatotrophic dwarfism
- Phocomelia
- Severe Asphyxiating thoracic dystrophy
- Anencephaly
- Severe hydrocephalus
- Severe encephalocele
- Bilateral renal agenesis (Potter's syndrome)
- Autosomal recessive polycystic kidney disease (infantile type)
- Trisomy 13
- Trisomy 18

Table 1: Lethal fetal anomalies.

1. The lethal malformations are confirmed by ultrasonography and or chromosomal analysis
2. At least two experts in neonatology and perinatology approve the malformation
3. Type of malformation should be documented in medical records of the mother
4. A written consent from parents or their delegates should be obtained
5. If the gestational age is more than 19 weeks of gestation, abortion is allowed if the continuation of pregnancy is expected to result in the death of its mother
6. If the gestational age is 19 weeks of gestation or less, abortion is allowed if its death is expected following delivery, or if the fetus has severe disabilities that cannot be cured
7. Abortion can be performed at any stage of pregnancy, if its death is medically confirmed in the womb of its mother
8. Palliative care should be offered for alive newborns with lethal malformations

Table 2: Steps of law process in aborting a malformed fetus.

pathophysiology have resulted in increases in the survival rates of the smallest, most vulnerable infants, and represent an enormous improvement in delivering prenatal, perinatal and postnatal care to the pregnant woman and her newborns. However, despite these advances, significant morbidity and disability persist. Biological survival depends not just on the presence of a given organ but on its functional maturation. For example, the alveolarization essential for survival is a process that includes anatomical, physiological and biochemical differentiation starting from about 24 weeks' gestation, progressing until term and continuing throughout the postnatal period and childhood. Advances in prenatal and neonatal intervention and techniques combined with dedicated, individualized care in Neonatal Intensive Care Units, have contributed to the increase in the survival of these infants. This paper discusses ethical and religious aspects of the limit of viability for extremely low birth weight neonates, including a recent fatwa issued in Saudi Arabia. Outcomes, sequelae and costs of care for these infants have been extensively reviewed elsewhere and are therefore not included here [14-16].

The decision to remove life-sustaining care from a critically ill baby is difficult and often distressing for parents and health care providers.

Many countries [17] fail to give specific recommendations stratified according to gestational age. They recommend that resuscitation is continued as long as there is reasonable hope of survival with an acceptable quality of life, and if the burden of therapies is endurable for the infant. When this burden outweighs potential benefits, intensive care is no longer justified and redirection of care to comfort measures could be acceptable. The American Academy of Pediatrics provides suggestions for counseling but fails to give any specific recommendations for treatment stratified according to gestational age. However, it does not recommend active intervention for infants under 23 weeks or with a 400 g birth weight [18].

Caregivers' Attitudes

It is known that end-of-life decisions (ELDs) are part of medical practice everywhere, even though with different frequencies in different countries. Several studies [19,20] have aimed to detect factors associated with attitudes toward ELDs and the decision of whether to make an ELD. Rebagliato et al. [21] explored the variability of neonatal physicians' attitudes in 10 European countries and the relationship between such attitudes and self-reported practice in end-of-life decisions. They found that the likelihood of physicians reporting that they set limits to intensive neonatal interventions when the neurological prognosis is poor is related to their attitudes. After adjusting for potential confounders, they found that country remained the most important predictor of physicians' attitudes and practices. Attitudes of obstetric and pediatric health care providers towards the resuscitation of infants born at the limits of viability were recently assessed by Lavin et al. [22]. Care providers (204 physicians and 539 nurses) at four tertiary perinatal care centers were asked about their attitude toward different gestational ages (22-26 weeks of gestation). The opinions of all the caregivers at each gestational age were as follows: 22nd week, the majority (69.2%) would strongly discourage resuscitation and an additional 19.3% would discourage it. 23rd week, The majority (70.0%) would either discourage (40.9%) or strongly discourage (29.1%) resuscitation. 24th week, The majority (63.3%) was either neutral (28.7%) or would recommend (34.6%) resuscitation. 25th week, The majority (85.3%) would either recommend (36.8%) or strongly recommend (48.5%) resuscitation.26th week, By the 26th gestational week, the majority (94.5%) would strongly recommend (78.8%) and an additional15.7% would recommend resuscitation. Thus there was agreement among physicians and nurses in recommending resuscitating infants with a gestational age of 25 weeks or more.

Parents' Views on End-Life-Care

For the most part, parents are not prepared for the end of their baby's life and are involved only when the poor outcome of their babies is inevitable. Parents usually indicate that when death is inevitable they do not want to prolong their baby's suffering. The parents' decision about end of life is almost always the result of their interactions with care providers and depends on the type of information with which the caregiver provides them. Parents need full knowledge about the condition of their babies to make such decisions and they tend to agree with their doctors if they are informed that the infant is critically or terminally ill, and will not survive. However, if parents feel that there is a small hope that their baby will survive, or the death of their baby takes longer than anticipated, parents may question the prognosis and have uncertainties about the decision made.

Islamic Legal Opinion

In the Islamic society, the difficult ethical decisions made by families and physicians faced with such situations are strongly influenced by religion. Recently the General Presidency of Scholarly Research and Ifta in Saudi Arabia issued a legal opinion (fatwa no. 231, March 6 2008) regarding premature infants born at less than 6 lunar months' gestation that is equal to 25 weeks' 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."

In this fatwa, the ultimate decision is thrown on the shoulders of the treating physician, who should be knowledgeable and up-to-date about the outcomes of these infants in order to decide on whether to offer full support or leave the infant to die without intervention. The

outcome of these infants varies from one place to another depending on geographical location and the facilities available, which makes the decision difficult to make. In addition, in the delivery room the time for making such a decision is limited. Any delay will expose the infant to more hypoxia and this will negatively affect the neurological outcome. I see the main benefit of this fatwa as that there are no legal consequences regarding any decision the physician makes.

This legal opinion is in accordance with the general view among pediatricians and other professional caregivers. The fatwa could be regarded as the first step in encouraging Islamic leaders to discuss this important topic with consultant pediatricians to establish guidelines for practicing physicians to follow throughout the Islamic world (Table 2).

Palliative Care

Palliative care begins with the diagnosis of a life-threatening/terminal condition, and continues throughout the course of illness regardless of the outcome. Therefore, understanding the right process of palliative care by the neonatal intensive care unit (NICU) personnel has a positive impact on families. When such measures are the focus of care, everyone in the NICU stands to benefit, including the newborn patient, his or her family, and the NICU staff. The main pillars of neonatal palliative care have been outlined in another article that we previously published. [23]. The main goal is to optimize the quality of life by active anticipation, prevention, and treatment of suffering. It emphasizes use of an interdisciplinary team approach throughout the continum of illness, placing critical importance on the building of respectful and trusting relationships. The care should include pain and symptomatic management, psychosocial support for family members, spiritual support for family members, and attention to the newborn's quality of life and best interests as determined through a culturally sensitive, negotiated, family-centered approach.

Conclusion

It is almost acceptable that medical and social factors limit access to safe abortion services in almost all the Muslim countries. All schools of Muslim law accept that abortion is permitted if continuing the pregnancy would put the mother's life in real danger. This is the only reason accepted for abortion after 19 weeks of gestation. Technological advances in the care of premature infants and improvements in clinical practice have led to increasing survival rates but also to increasing illness acuity in surviving low birth weight infants. Decisions regarding the initiation of resuscitation and withdrawal of treatment create difficult emotional and ethical dilemmas for parents and health care providers. From this perspective it is clear that the decision not to resuscitate is debatable. The Islamic legal opinion (fatwa) described in this paper enables a line to be drawn for the limit of viability by stating that infants born at less than 6 lunar months may be offered no resuscitation if their physicians see no benefit for the infant in resuscitation. This legal opinion fits well with the general view among pediatricians and other professional caregivers.

References

1. United States. Congress. Senate. Committee on Health, Education, Labor, and Pensions. Subcommittee on Children and Families (2003) Birth defects: strategies for prevention and ensuring quality of life : hearing before the Subcommittee on Children and Families of the Committee on Health, Education, Labor, and Pensions, United States Senate, One Hundred Seventh Congress, second session on examining public health issues related to birth defects, focusing on strategies for prevention and ensuring quality of life. U.S. G.P.O.
2. Statham H (2002) Prenatal diagnosis of fetal abnormality: The decision to terminate the pregnancy and the psychological consequences. Fetal Matern Med Rev 13: 213-247.
3. Rauch ER, Smulian JC, DePrince K, Ananth CV, Marcella SW, et al. (2005) Pregnancy interruption after second trimester diagnosis of fetal structural anomalies: The New Jersey Fetal Abnormalities Registry. Am J Obstet Gynecol 193: 1492-1497.
4. Mansfield C, Hopfer S, Mareau TM (1999) Termination rates after prenatal diagnosis of Down syndrome, spina bifida, anencephaly, and Turner and Klinefelter syndromes: a systematic literature review. European Concerted Action: DADA (Decision-making After the Diagnosis of a fetal Abnormality). Prenat Diagn 19: 808-812.
5. World Abortion Policies (2007) United Nations, Department of Economic and Social Affairs, Population Division.
6. http://en.wikipedia.org/wiki/Race_%28classification_of_humans%29
7. Schechtman KB, Gray DL, Baty JD, Rothman SM (2002) Decision-making for termination of pregnancies with fetal anomalies: analysis of 53,000 pregnancies. Obstet Gynecol 99: 216-222.
8. English J (1975) Abortion and the concept of a person. Can J Philos 5: 233-243.
9. Rosen Judith C (1990) A legal perspective on the status of the fetus: Who will guard the guardians?. In Doerr ED, Prescott JW, Americans for Religious Liberty (Eds.), Abortion Rights and Fetal 'Personhood' (2nd Edn.), Centerline Press, Long Beach, California, 29-50.
10. Teresa Marino (2012) Prenatal Diagnosis for Congenital Malformations and Genetic Disorders.
11. Hessini L (2007) Abortion and Islam: policies and practice in the Middle East and North Africa. Reprod Health Matters 15: 75-84.
12. Pignotti MS, Donzelli G (2008) Perinatal care at the threshold of viability: an international comparison of practical guidelines for the treatment of extremely preterm births. Pediatrics 121: e193-198.
13. Sankaran K, Chien LY, Walker R, Seshia M, Ohlsson A, et al. (2002) Variations in mortality rates among Canadian neonatal intensive care units. CMAJ 166: 173-178.
14. Lucey JF1, Rowan CA, Shiono P, Wilkinson AR, Kilpatrick S, et al. (2004) Fetal infants: the fate of 4172 infants with birth weights of 401 to 500 grams--the Vermont Oxford Network experience (1996-2000). Pediatrics 113: 1559-1566.
15. Meadow W1, Lagatta J, Andrews B, Caldarelli L, Keiser A, et al. (2008) Just, in time: ethical implications of serial predictions of death and morbidity for ventilated premature infants. Pediatrics 121: 732-740.
16. Saigal S1, Stoskopf B, Boyle M, Paneth N, Pinelli J, et al. (2007) Comparison of current health, functional limitations, and health care use of young adults who were born with extremely low birth weight and normal birth weight. Pediatrics 119: e562-573.
17. Shankaran S1, Johnson Y, Langer JC, Vohr BR, Fanaroff AA, et al. (2004) Outcome of extremely-low-birth-weight infants at highest risk: gestational age < or =24 weeks, birth weight < or =750 g, and 1-minute Apgar < or =3. Am J Obstet Gynecol 191: 1084-1091.
18. Al-Alaiyan Saleh, Al-Abdi Sameer, Alallah Jubara, Al-Hazzani Fahad, AlFaleh Khalid (2013) Pre-viable Newborns in Saudi Arabia: Where are We Now and What the Future May Hold? Current Pediatric Reviews 9: 4-8.
19. American Academy of Pediatrics Committee on Fetus and Newborn, Bell EF (2007) Noninitiation or withdrawal of intensive care for high-risk newborns. Pediatrics 119: 401-403.
20. Cuttini M, Nadai M, Kaminski M, Hansen G, de Leeuw R, et al. (2000) End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries. EURONIC Study Group. Lancet 355: 2112-2118.
21. Rebagliato M1, Cuttini M, Broggin L, Berbik I, de Vonderweid U, et al. (2000) Neonatal end-of-life decision making: Physicians' attitudes and relationship with self-reported practices in 10 European countries. JAMA 284: 2451-2459.
22. Lavin JP Jr1, Kantak A, Ohlinger J, Kaempf JW, Tomlinson M, et al. (2006) Attitudes of obstetric and pediatric health care providers toward resuscitation of infants who are born at the margins of viability. Pediatrics 118: S169-176.
23. Al-Alaiyan S1, Al-Hazzani F (2009) The need for hospital-based neonatal palliative care programs in Saudi Arabia. Ann Saudi Med 29: 337-341.