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Ethical Dilemmas in Neonatology – Four Theoretical Cases and Three Monotheistic Approaches: A Pilot Study

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ABSTRACT:

Background: Israel's population is diverse, with people of different religions, many of whom seek spiritual guidance during ethical dilemmas. It is paramount for healthcare providers to be familiar with different religious approaches.

Objectives: To describe the attitudes of the three major monotheistic religions when encountering four complex neonatal situations.

Methods: A questionnaire related to four simulated cases was presented to each participant: a non-viable extremely premature infant (case 1), a severely asphyxiated term infant with extensive brain damage (case 2), a small preterm infant with severe brain hemorrhage and likely extensive brain damage (case 3), and a term infant with trisomy 21 syndrome and a severe cardiac malformation (case 4).

Results: Major differences among the three religious opinions were found in the definition of viability and in the approach towards quality of life.

Conclusions: Neonatologists must be sensitive to culture and religion when dealing with major ethical issues in the neonatal intensive care unit.

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KEY WORDS: bioethics, neonatology, Christianity, Islam, Judaism

B ioethics is defined as, "the branch of applied ethics which studies practices and developments in the biomedical fields" [1]. It is a shared, reflective process of examination that provides, "moral reasoning to biomedical practice" [1].

The Israel population comprises people of Jewish ancestry and religion (75.6%) and those of Arab ancestry (20.6% Muslim, 4.2% Christian). In such a context, ethical decision makers have to be cognizant and respectful of the social and religious context of all parties involved, including family members and caretakers.

In this pilot study, we examined the attitudes and practical recommendations of leading Israeli clerics from the three major Israeli monotheistic religious groups (Orthodox Jewish, Sunni Muslim, and Catholic Christian). We examined the responses

of these clerics when faced with four theoretical cases based on actual experiences gathered in our neonatal intensive care unit (NICU) in Jerusalem.

PATIENTS AND METHODS

We presented four theoretical cases of infants who were eligible for palliative care (as defined by Van Mechelen [2]) to 12 clerics. Eight participants were rabbis who were members of the Puah Institute, an organization of Jewish Orthodox leaders who specialize in the interface of Jewish law (Halacha) and fertility and childbearing. Two participants were Catholic priests, one of whom was the official governmental representative of the Christian faith for the National Israeli Bioethics Committee. One was a Sunni Muslim Imam, and another was a Sunni Muslim Cadi (religious judge) and member of the Islamic Supreme religious court.

For each case, the same open-ended question was asked, "In the case presented, what is your religious/ethical approach?" Since each cleric was not necessarily an expert in neonatal medicine, one of our staff members (M.S.S.) explained the medical aspects of each case, as necessary. Each cleric responded in writing, either before or after consulting with other clerics from the same denomination.

THE FOUR CASES

• Case 1: A non-viable extremely premature infant

"You are faced with an extremely low birth weight infant, who was born at a gestational age of 22 weeks + 4 days to a young couple after fertility therapy. The baby is crying, has moderate respiratory effort and a normal heart rate. At the current time, in this hospital, as well as in other units in the country, there are no survivors at this gestational age."

Case 2: A severely asphyxiated term infant with extensive brain damage

"You are faced with a term infant with neonatal encephalopathy post-placental abruption. He is currently ventilated, has been weaned from hypothermia, and receives several medications for prolonged seizures. Magnetic resonance

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imaging reveals extensive brain damage. The infant is hemodynamically stable. He needs tracheostomy and gastrostomy for palliative care."

Case 3: A small preterm infant with severe brain hemorrhage and likely brain damage

"You are faced with a small premature infant born at 27 weeks gestation, who on day 3 experienced an event of acute deterioration. Head sonography revealed an extensive bilateral grade IV intraventricular hemorrhage. According to the attending neonatologist, survival is doubtful, and if the infant survives, significant neurodevelopment impairment is expected. If there is further deterioration, should cardiopulmonary resuscitation (CPR) be performed?"

Case 4: A term infant with trisomy 21 syndrome and a severe cardiac malformation

"You are faced with a term baby born with trisomy 21 and diagnosed with hypoplastic left heart. According to the pediatric cardiologist, for survival the baby will require three major successive operations during the first year of life, with a survival rate of 60–70%."

RESULTS

The opinions by clerics are as follows, case by case.

• Case 1: A non-viable extremely premature infant

- a. Christian Catholic: One of the two Roman Catholic priests stated that the case includes a premature delivery and not an abortion. From a Catholic Christian standpoint, the important decision makers must be the family together with the local priest of the family's church. The issues at stake include the fate of this child in a holy world and issues of human dignity. Since we must rely on the medical team's experience and expertise, and since they state that there are no survivors in the current medical settings, we advise that only comfort care be provided to this dying patient. As with all born children, this infant should be baptized and buried according to Christian customs. This Catholic Christian opinion is based on article 37 of the Pontifical Council for Pastoral Assistance to Health Care Workers, the charter for healthcare workers [3]. The other Catholic priest stated that issues of life and death are within God's supreme authority, thus we are obligated as human beings to care for the child.
- b. Sunni Islam: Both clerics stated that a fetus older than 120 days post-conception is viable, and all efforts to save a life are justified. In addition, in this case the baby is crying and has all the rights that a normal human being inherits, he should be named and his/her caretakers all have

- obligations towards him, including giving him proper burial. We thus advise at this point that full medical care be provided, including ventilator support and resuscitation measures [4].
- c. Jewish Orthodox: Since the predicted survival rates are extremely low, we advise that only comfort care be provided to this dying patient. However, if there is uncertainty about the length of gestation and the baby shows signs of life, such that the baby may be closer to 23–24 weeks of gestation, full medical care should be provided, since at this gestational age infants are viable [5]. If there is certainty about the dates, and after comfort care the patient dies, he/she ought to be buried in a specifically designed place in a Jewish cemetery.

• Case 2: Term severely asphyxiated infant with extensive brain damage

- a. Christian Catholic: From a Catholic Christian standpoint, an overarching principle is that the decisionmakers involved must include the family together with the local priest from the family's church. The issues at stake include life and life expectancy of a human being with severe handicaps. Devout Catholic Christians may be able to see the secret love of God in such a child with a severely limited potential for social interactions. As there is no brain death, both procedures (tracheostomy and gastrostomy) are considered as extreme procedures and thus may not be mandatory and the final decision should be left to the parents. Moreover, the priest must analyze the ability of the family and the community to care for such a child, as suggested by Clarke [6]. Such a child may be classified by McCormick as a "handicapped newborn who has a potential for human relationships but whose potential is utterly submerged in the mere struggle for survival" [6]. Issues of baptism and burial are similar to those of case number 1.
- b. Sunni Islam: Both clerics noted that this issue is controversial within Islam Some scholars say that because of the neurodevelopment impairment non-life saving invasive procedures should be performed only at the parents' request. Others state that the treatment is mandatory only if the treatment ensures the cure of the patient in a way "water will save the thirsty of death" [7]
- c. Jewish Orthodox: Both procedures (tracheostomy and gastrostomy) should take place in a facility with facilitate palliative care [8]. There is no justification ever to cause death and withdrawal of a respirator from a patient who is dependent on it is considered an act of hastening death. Also, avoidance of providing food and fluids is regarded as a form of hastening death. In addition, these measures serve as palliative care procedures, and hence should be performed for the benefit of the infant.

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• Case 3: Severe brain hemorrhage with likely brain damage in a small preterm infant

- a. Christian Catholic: This case is linked to issues similar to those of case 2, but this child is not even stable from a medical standpoint. Thus, in such a case, the request to not perform CPR is logical, since one must not use extraordinary measures to sustain life at all price. In any event, the child must be baptized as in case numbers1 and 2.
- b. Sunni Islam: CPR should be performed because there is a need to sustain life at any price. Neurodevelopmental outcome is irrelevant. It is in God's hands. This response is based on the Holy Quran, which states: We decreed on the Children of Israel that whoever kills a soul unless for a soul or for corruption [done] in the land, it is as if he had slain mankind entirely. And whoever saves one, it is as if he had saved mankind entirely [9].
- c. Jewish Orthodox: There is no need for CPR. If cardiac arrest occurs, and there is strong evidence for short life expectancy, there is no requirement to resuscitate [10]. Nevertheless, palliative and supportive care is required.

• Case 4: A term infant with Down syndrome and a severe cardiac malformation

- a. Christian Catholic: According to the Church, children with Trisomy 21 must be treated as regular children by all accounts [11]. The fact that the cardiac surgery is accompanied with a very high mortality risk is acceptable particularly if there is no medical alternative. Thus, if surgery is essential, statistics are not relevant, and surgery should be performed.
- **b. Sunni Islam:** Surgery should be performed if it is essential for the child's survival, as pointed out in cases 2 and 3.
- c. Jewish Orthodox: The issue of whether or not the child has trisomy 21 is irrelevant as far as life and death decisions are concerned. An infant with Down syndrome has the same rights and claims for life as any other baby. As for the surgical cardiac repair, recommendations should be determined by the success rate of the procedure(s) required. Surgery is indicated if it is not experimental and if it does not have an immediate death rate of 50% or more [12].

DISCUSSION

In this study, we presented selected clergymen of the three major monotheistic religions with a few frequently encountered ethical dilemmas from the NICU. The answers we obtained reflected the variability in approaches among selected representatives of the three monotheistic religions. Understanding of this variability is particularly important for countries whose population has various religious backgrounds. NICU hospitalization is a trau-

matic event for families, and many parents during that time seek spiritual help and support from their clergymen. Our goal was to emphasize the subtle, but highly significant, differences that exist among the various monotheistic clerics (Catholic Christianity, Sunni Islam, and Orthodox Judaism) that we approached.

Although we designed the questionnaires for highly respected clerics in the field of medical ethics in Israel, the views they expressed may not be considered the official, or even a consensus, response opinion of their religious peers. However, it seems that there was consistency among clerics of the same religious obedience. It has been our experience that even within one branch of Orthodox Judaism, there are controversies on issues of medical ethics. For example, devout Orthodox Jews are mandated to choose a rabbi and stick firmly to his decision without seeking advice elsewhere [13]. Thus, it is clear to us that the relatively small number of clerics involved from each religion in this pilot study cannot reflect all the nuances that a much larger number of clerics could provide.

Another limitation of our study is the fact that the questions were open-ended to let each individual fully explain the basis for his answer, which precludes the performance of any kind of quantitative analysis.

Our study dealt with only a few of the very many bioethical questions that we ask daily in the NICU. Among them: Does a newborn have the same rights as an adult? Is there an ethical difference between a healthy newborn and a neurologically impaired newborn? Should we value life itself, or mainly the quality of life? Are financial considerations appropriate to the ethical deliberations in the decision-making process? Which treatments could be withheld and/or withdrawn? Who should be regarded as the best advocate on behalf of the baby - his/her parents? The medical team? The hospital ethics committee? [14]

Natarajan and Pardo [15] stated that "clinicians must recognize any biases they have and strive to guide parents based on the family's values, not the professional's." As stated by Solomonov et al. "Making available the highest standard of medical care is a humanitarian imperative" [16]. This however cannot be achieved by blindly applying technology at the expense of the highest moral standards. Following this statement and recognizing the diversity of the population we are serving, we hope that these four theoretical cases will help practicing neonatologists by preparing them to understand and respect the various nuances of parental decision making based on their spiritual background.

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Capsule

Supporting tumor suppression

The protein PTEN is a phosphatase and tumor suppressor whose activity is often decreased in human cancers. Thus, reactivating such a protein could potentially be an effective therapy against cancer. **Lee** et al. identified a ubiquitin E3 ligase (WWP1) as a PTEN-interacting protein that modifies PTEN and inhibits its tumor suppressive activity. Depletion of WWP1 increased dimerization and membrane recruitment

of PTEN. A natural compound found to be a pharmacological inhibitor of WWP1 inhibited tumor growth in a mouse model of prostate cancer. Thus, reactivation of the tumor suppressor PTEN may provide a strategy for battling tumors.

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Eitan Israeli

Capsule

Dissecting risk for new mothers

Marfan syndrome is a connective tissue disorder associated with manifestations in multiple organ systems. The aorta is a key site affected by this syndrome, and female patients are at risk for aortic dissection associated with pregnancy and childbirth. Traditionally, this risk has been ascribed to labor-induced stress, but aortic dissection often occurs relatively

late following birth. Using mouse models of Marfan syndrome, **Habashi** et al. found that oxytocin, the hormone involved in milk letdown, plays a key role in aortic dissection and identified several potential approaches for preventing this complication.

Sci Transl Med 2019; 11: eaat4822 Eitan Israeli

Capsule

Epigenetic enablers of B cell activation

Initiation of immunoglobulin class switching and somatic hypermutation during B cell activation requires tightly regulated expression of the activation-induced cytidine deaminase (*Aicda*) gene. **Lio** et al. investigated how the enzymes responsible for depositing 5-hydroxymethylcytosine epigenetic marks on genomic DNA (TET2 and TET3) contribute to regulation of *Aicda* expression by studying B cells from

mice in which the two enzymes can be inducibly deleted. Two key elements within the *Aicda* superenhancer are marked by TET2 and TET3 for progressive hydroxymethylation followed by demethylation, thereby facilitating chromatin accessibility and *Aicda* expression.

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