Fetuses with Neural Tube Defects: ethical approaches and the role of health care professionals in Turkish health care institutions

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Neural tube defects (NTDs) are very serious malformations for the fetus, causing either low life expectancy or a chance of survival only with costly and difficult surgical interventions. In western countries the average prevalence is 1/1000–2000 and in Turkey it is 4/1000. The aim of the study was to characterize ethical approaches at institutional level to the fetus with an NTD and the mother, and the role of health care professionals in four major centers in Turkey. The authors chose perinatology units of four university hospitals and prepared questionnaires for the responsible professionals concerning their own and their institution's ethical approaches to the fetus with an NTD and the mother. The investigation revealed that there were no institutional ethical frameworks or ethics committees available to professional teams in the units. The roles of the health care professionals and their individual decisions and approaches based on ethical principles are described. The ethical decision-making process concerning fetuses with NTDs, examples of institutional approaches to the topic and institutional frameworks, and the role of nurses and other health care professionals are all discussed, based on a literature review. The authors suggest that institutional ethical frameworks, ethics committees, professionals' ethics education and multidisciplinary teamwork should be established for critical situations such as fetuses with an NTD.

Introduction

Neural tube defects (NTDs) are important health problems for fetuses, newborn babies and their related social networks. The most common NTD is spina bifida (SB), which is the defective closure of the vertebral column. There are different forms, ranging from mild to severe,[1] from the occult type with few signs to a completely open spine. In spina bifida cystica the protruding sac contains meninges (meningocele), spinal cord

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(myelocele) or both (meningomyelocele). SB is commonly seen in the lumbar, low thoracic or sacral regions, and extends for three to six vertebral segments.

When the spinal cord is involved, varying degrees of paralysis occur below the affected level. SB is a static congenital NTD resulting in continuously evolving disease of multiple organ systems. Orthopedic problems, malfunctioning of the sphincters of the bladder and rectum, severely damaged kidneys, hydrocephalus and other congenital anomalies may be present.[1,2]

NTDs occur in 1.4–2/1000 pregnancies and are the second most common major congenital anomaly worldwide (cardiac malformations are first). Anencephaly accounts for one half of all cases of NTD and is incompatible with life;[3] with treatment, 80–90% of infants with SB survive with varying degrees of disability.[4] In a nationwide research project carried out under the guidance of a medical school in Turkey, NTDs were reported to be very common, in approximately 3.5–4/1000 pregnancies.[5] In France the prevalence ranges from about 0.5 to 6 per 1000 births.[6] The Texas-Mexico population has a prevalence of 1.6/1000 NTDs, while in the US it is 0.8–1/1000.[4] In Canada, in 1998–2000 the prevalence of NTDs was 1.28/1000, declining from 1.89/1000 in 1992–1997 after the fortification of flour with folic acid.[7] In China, the prevalence of isolated NTD in female babies (2.57/1000) was higher than in male babies (1.4/1000).[8] In 20 regions of Europe, the average occurrence of SB is declared as 1.2/1000, while the ratio of SB to anencephaly is 1.3:1.0.[9]

Most importantly, NTDs are among the few birth defects for which primary prevention is possible; prenatal screening and diagnosis are widely available, and prenatal therapy is being investigated. The prenatal use of folic acid and genetic counseling are examples of preventive measures.[10,11] The common diagnostic methods used during pregnancy are the detection of alpha-fetoprotein in serum, amniocentesis between 14 and 16 weeks of pregnancy, and detailed ultrasonographic follow-up of pregnant women by hospital perinatology units.[2] These are important because decisions about these fetuses are easier if medical indications give accurate, clear and promising information about outcome.[12,13]

Abortion and NTDs

It is the application of abortion in these cases that creates serious discussion, because ethical conflict between the fetus's right to life, the mother's autonomy and health caregivers' adherence to the principle of beneficence lead to dilemmas that must be resolved.[14–16] Abortion has always raised many medical, social and moral questions, even in ancient Greece, Egypt and Mesopotamia. Studies have tried to present arguments and attempted to answer these questions in a rational way throughout the last century, but uncertainties still exist.[17–27]

In Turkey, abortion is legally regulated. Abortion on demand by the mother without any medical indications is permitted until 10 weeks of pregnancy, but abortion for fetuses with malformations has a different legal status. There are no clear limits for the time of intervention but it is allowed after 10 weeks of pregnancy if the fetus has serious health problems. No upper limit for the time of intervention for fetuses with congenital malformations is included in the last amendment to the demographic planning legislation of 1965 (Article 2827) in 1983.[28]

Around the world abortion is debated from many angles. For example, in Germany the debate is around whether to regard abortion as unlawful or to allow it by setting the beginning of a right to life at birth.[29] In Nigeria[30] the concern is about legalizing abortion. This is also the case in Zimbabwe,[31] where a women's action group believes that every woman should decide about her life and be in charge of her destiny. In Brazil[32] the legalization of abortion on demand until the 12th week of pregnancy is currently being discussed. Another debate concerns the abortion of anencephalic fetuses to be used for transplantation. It has been proposed that abortion of such fetuses should be permitted at any time in all countries on the grounds that they never have any brain life.[33] Another study from the USA reports that courts and legislatures are increasingly being called upon to restrict the autonomy of pregnant women and the debate there is about prosecution for decisions made during pregnancy.[34]

Deciding on a right time for abortion that is acceptable to the families concerned is one of the major problems raised in the context of NTDs, because some cases are diagnosed late.

Life expectancy and decisions to terminate or treat

In addition to the debate about abortion, SB has the possibility of many alternative treatments and it has the longest life expectancy among the NTDs, especially when compared with anencephaly, hydrocephaly, etc. Those affected require lifelong surveillance and co-ordinated management involving patients, parents, nurses, general practitioners, neurologists, physiotherapists, occupational therapists, social workers, neurosurgeons, urologists, orthopedic surgeons, and other health professionals.[2]

The decision of whether or not to treat must be made before neurosurgery is undertaken because closure of the defect assures at least temporary survival. This decision depends on the type of lesion, any associated defects, the infant's health status in general, the available treatment resources including ongoing care, the family's desire and determination and the estimated potential for the patient's life.[2,13] Long-term follow-up is necessary regardless of initial treatment.[35]

Urgent neurosurgical repair, shunt procedures for hydrocephalus, monitoring of kidney function and orthopedic care are the main treatment decisions. The choice of treatment time, such as after birth or surgically *in utero*, and economic cost are other topics currently being debated.[36]

Doctors need reliable data on the possible outcome of a pregnancy in order to help parents who are faced with difficult decisions about termination or about treatment after birth. It has also been recognized that morphological fetal central nervous system findings detected in early development are not always the final features and may change developmentally or chronologically *in utero*. Prerequisites have to be established for the use of advanced neurosurgical techniques in the management of fetal central nervous system abnormalities.[2,36] Peritoneal dialysis and the establishment of a ventriculoperitoneal shunt need early evaluation by a pediatric surgeon and a neurosurgeon.[37] Recent literature reviews cover: desmopressin treatment for nocturnal bedwetting; teaching children with SB and fecal incontinence how to defecate; fashioning of a continent appendicostomy or cecostomy, surgically,

endoscopically or radiologically; and the long-term follow-up of children with SB regardless of their initial treatment.[38,39] A research group from Istanbul, Turkey,[40] reports that 52 children with meningomyelocele were treated at Cerrahpasa Medical Faculty Department of Neurosurgery between July 1994 and July 1995. The results showed that 48 women were followed during their pregnancy. In 22, open SB was never suspected; a definitive diagnosis was made in only 12 pregnancies. Forty-four families said that they would have accepted abortion if they had known the diagnosis in time. Back repair was performed on 22 children; the other families did not accept surgical intervention.[40]

In the results of another study from Turkey[41] the authors report on the therapeutic outcome in 159 children who were treated surgically at Cerrahpasa clinics between 1983 and 1993. Twenty-four per cent were neonates when operated on and 75% of the operations took place during the first six months after birth. Eight children died in the early postoperative period. Only 67 were followed for 30 months; it was considered that 38 would be dependent on others.

Variance in approaches world-wide

The application of preventive measures, diagnostic methods, abortion, treatment decisions or any type of euthanasia in the health care context differs greatly between countries. There is more support for aggressive and intensive prenatal treatment of SB in Asia than in Europe and North America. The marker alpha-fetoprotein is not widely accepted for prenatal diagnosis in Asia, nor is the prophylactic administration of folic acid part of routine care. Morphological analysis by neuroimaging, especially with magnetic resonance imaging, is well developed in Asian countries such as Japan and Korea.[42] In the province of Quebec, Canada,[43] anglophone physicians show a greater acceptance of abortion than their French-speaking colleagues.

In a study carried out in France,[44] it was shown that physicians opposing termination of pregnancy were concerned that the severity of the anomaly was not sufficient justification for termination, but that they would be prepared to modify their position if diagnosis were possible in the first trimester. The EUROCAT Working Group reported that the impact of early prenatal diagnosis was to increase the rate of pregnancy termination.[9]

Ethical issues related to the medical facts above

Children represent the future of families, communities, nations and the world. They require special protection because of their immature status. This study focuses on the issues associated with infants with an NTD. These issues have led to difficult ethical dilemmas associated with high-technology medical care, economic considerations, the moral status of the infant, the sacredness of life, quality of life, euthanasia, abortion, the autonomy of the mother, the fetus's right to life, proxy decision making, and what guidelines should be followed when making these decisions. These dilemmas are relevant to the medical topics introduced above and bring the ethical implications and

the role played by health care professionals to the fore.[45] There are serious ethical implications at individual, institutional and societal levels. We will focus primarily on the institutional level of the problem, while providing additional information at individual and societal levels as needed.

This study examines the experiences of five units in four tertiary care hospitals in Turkey in the context of institutional ethics committees and individual ethical approaches to critically ill newborns or fetuses with NTD. Their story starts with the medical indications of prevention at preconception and proceeds to the civil rights of adults with impairments. Our small research project is the core of the study and will be supplemented with the results of a literature search. In addition, we will address the role of health care professionals in decision making and caring for the mothers and infants in clinical contexts, and relate this to institutional ethical frameworks and committees in critical care situations.

Objective

The objective of this study was to assess and characterize the ethical framework and decision-making rationales at institutional level for clinical ethics practice for fetuses with NTDs in four major centers in Turkey. The results of interviews conducted at the four selected centers are presented. The study is used as the foundation for a broader discussion of the issues based on a review of the literature.

Some strategies and the role of ethical frameworks for institutions and health care professionals, especially nurses, will be discussed and our approach to decision making will be presented. We have chosen to focus on SB because this is the most common type of NTD and has the longest life expectancy.

Method and settings

Four university hospitals with perinatology units were selected. Babies with SB are not followed up at every health center; they are usually referred to these hospitals.

A questionnaire was prepared concerning ethical approaches to affected pregnancies and the authors visited the selected university hospitals, which were in three major metropolitan areas of Turkey, representing three different geographical regions. The questionnaire was administered to randomly selected senior physicians and nurses in departments of gynecology and obstetrics. Interviews were preferred instead of written answers because some of the questions were open ended and related to ethical matters and because the interviewees may have been unfamiliar with the context of some questions and therefore may have needed some explanations. Details of some patients were required, which have been possible to obtain by written answers. Some answers needed further questioning for clarification. The aim was to discuss the ethical frameworks used by the units by means of the open-ended questions.

Interviews were carried out with the health care professionals working in four tertiary care hospitals that also have medical schools (university hospitals), or with

specialist perinatology health care professionals if there was not a separate unit in the hospital. We chose these institutions because complicated cases such as fetuses with malformations or with a risk of malformation are mostly referred from primary or secondary health care institutions to those centers to be evaluated and followed up. In one of the institutions, the pediatric surgeons were especially interested in the study. They had established the Turkish Society for Spina Bifida, which has branches in other cities and is working intensively for the educational, social and medical needs of children with SB.

The hospitals have a bed capacity of between 1000 and 1500. The physicians were comparable in terms of their sociodemographic characteristics. Most of them were men aged between 45 and 55 years, with between 15 and 20 years of experience, and they all had children themselves.

Pregnancies at risk or complicated by congenital malformation pose many ethical dilemmas and health care professionals and families face difficulties when making decisions. We wanted to ascertain the existence of institutional ethics committees[45] and ethical frameworks to support or guide the decision-making process.

The staff physicians and nurses were already knowledgeable and experienced but they were few in number. In one clinic, one other doctor, apart from the perinatologist, was also chosen randomly. One justification for random selection is to find out if there is a standard institutional protocol that is known by all professional staff to guide them when they are exposed to an ethical problem. Given the limitations, the optimum way to avoid bias as much as possible was to select the participants randomly. To minimize the bias further, no information was provided before interview. The purpose was to identify the standard and available ethical framework employed by these professionals and the frameworks of which they were aware. Three physicians and two nurses were interviewed from each center, including those working in pediatric surgery. Altogether, 15 physicians and 10 nurses from four institutions and five units participated. This was a small study, which was one of its limitations.

There were two purposes in preparing the questions. The first was to identify the existence of ethics committees, institutional protocols concerning ethical approaches, and educational programs providing teaching on ethical sensitivity. The second was to ascertain if professionals or institutions adhere to codes and theories of ethics, ethical principles or methods that facilitate health professionals' thinking about the complexities of the ethical problems they face in practice when dealing with pregnancy complications.

The questionnaire had two parts, the first with three purposive questions and the second with nine, with relevance to the first part. Answers to the first part were expected to be either negative or positive and were about the existence of institutional ethics committees, ethics consultation centers, ethical guidelines, international and national codes, bases for decision making, and the presence of decision makers. This part sought information on formal institutional ethics discussions.

The second part had nine questions, which were open ended. The narrative answers were reduced according to the ethical principle, basis, rule or theory they covered.

The narrative questions could be grouped as follows:

- Question 6 was a control question for the 'use of international codes of ethics question' in the first part of the questionnaire. The participants were therefore

asked for a second time if any codes were being followed. By asking twice, the participants had a chance to remember any standard protocol they were using. This demonstrated how much they were orientated to the topic.

- Question 4 was initially a 'yes/no' question, but then the participants were asked if their answer depended on legislation, the organization or an ethical approach.
- Questions 5, 8 and 9 were designed to show if professionals had a paternalistic approach (if they might question their bias or values), or depended on the principles of beneficence or autonomy.
- Questions 1 and 2 attempted to reveal the ethical basis for decisions made by health care professionals (decision-making protocols).
- Questions 3 and 7 probed the role of decision makers. Did they collaborate for the benefit of the patients; and were they aware of their values and conflicts? (professional training in ethical decision-making).

Analysis

The questionnaire answers are summarized and grouped in Table 1. This was a retrospective, descriptive, small study.[46] Bias may have been lessened by the positive/negative statements about the existence of ethical tools (committees, written protocols, guidelines etc.) and, if the answers from the different centers could be shown to agree with each other to a marked extent, then confidence in the results could be established.

The interviews were carried out face to face. Most of the answers were either positive or negative, but some questions were designed to lead the participants on to narrative explanations, but the answers could be reduced because of the ethical facts that were purposively sought when the questions were prepared.

The answers were qualitative variables and they were measured nominally. In terms of statistical methods,[46] numerical operations were not performed on nominal scale variables, even though numerical codes were used to define categories. The appropriate descriptive statistics were the frequency of observation and the relative frequency in the various categories.

Findings and evaluation

The answers were reduced according to the purpose of each question (i.e. whether it was concentrated on an ethical issue, principle, method or decision-making process).

Formal discussions

None of the hospitals have an ethics committee or any ethics consultation service in the gynecology department. In three hospitals, there is a clinical committee consisting of a gynecologist, a perinatologist, a genetics specialist and sometimes another specialist relevant to the status of the case. In one of these, a special clinical committee of pediatric surgeons and another committee in the perinatology unit hold consensus meetings about babies with malformations.

None of the university hospitals have specific protocols about the application of codes of ethics or about ethical approaches, but the health care professionals of the

Table 1 Questionnaire answers

Questions and answers	No. physicians ($n = 15$)	No. nurses ($n = 10$)	No. physicians + nurses ($n = 25$)	%
Is there an ethics committee in your institution? (1st part question)				
Yes	0	0	0	0
No	15	10	25	100
Is there a protocol for ethics in your institution? (1st part question)				
Yes	0	0	0	0
No	15	10	25	100
Are there consensus meetings for decision making? or Are there international codes that are followed for making decisions? If yes, which ones? (1st part)				
Yes	3[a]	2[a]	5	20
No	12	8	20	80
Is abortion carried out at this university hospital? (question 4)				
Yes	12	8	20	80
No	3	2	5	20
Is there an institutional consensus decision on the latest abortion time for a fetus with malformations? (question 1)				
Yes	15	10	25	100
No	0	0	0	0
Do you collaborate with radiologists to monitor pregnant women at risk? (question 3)				
Yes	3	2	5	20
No	12	8	20	80
Do you follow any international codes of ethics at your institution? (question 6)				
Yes	3[a]	2[a]	5	20
No	12	8	20	80
Do you agree to follow up a pregnant woman carrying a malformed fetus until birth if she refuses abortion? (question 5)				
Yes	15	10	25	100
No	0	0	0	0
Do you have special meetings to discuss the decision of the mother? Do they wish for euthanasia for their child? Is the mother's decision healthy or not? (questions 5 and 2)				
Yes	0	0	0	0
No	15	10	25	100

Table 1 (*Continued*)

Questions and answers	No. physicians ($n = 15$)	No. nurses ($n = 10$)	No. physicians + nurses ($n = 25$)	%
Do you have any educational programs to overcome the burnout syndromes of professionals? (question 7)				
Yes	0	0	0	0
No	15	10	25	100
Do you educate professionals about their values? Are nurses included in the decision making process? (question 7)				
Yes	0	0	0	0
No	15	10	25	100
Do you evaluate cases retrospectively as feedback for future healthier decisions? (question 8)				
Yes	8	8	16	64
No	7[b]	2	9	36
In *in-vitro* fertilization units, do you have an ethical approach to procreative choice and beneficence? (question 9)				
Yes	3	2	5	20
No	12	8	20	80

[a]Royal College of Physicians, London.
[b]But they did remember the cases.

departments of gynecology and obstetrics organize meetings or follow patients' progress, usually with the perinatology professionals. None of the four university hospitals' gynecology and obstetrics departments follow specific methods for deliberation and justification or rational decision making on the resolution of dilemmas. Any patients to be discussed in departmental committee meetings are referred only by the physician in charge of that patient. In one of the hospitals, the final decision is made by the head of department; this is an administrative position. In other clinical committees, decisions are made by majority vote. Cases for discussion cannot be suggested by nurses or patients, and nurses do not take part in the decision-making process. In one hospital, the committee's decision is explained to the family and eventually the family's decision is respected. In the other university hospitals parents are informed about the situation and abortions are also carried out on demand.

Decision-making protocols

In none of the clinics do they tend to abort a fetus after 24–25 weeks of pregnancy. They do not use feticide, but assist the mother at the birth. This has become almost a

consensus decision. The institutions need at least three signatures to terminate a pregnancy with a fetus with severe malformations, even before 24 weeks. In two institutions they organize monthly perinatology mortality meetings with a pathologist and learn the outcomes of the fetuses retrospectively, which seems important for justification of the decisions.

In all of the clinics, no requests have been received from parents for euthanasia for disabled babies. Although they have never practiced euthanasia in these clinics, in one of the hospitals it is claimed that the parents usually do not take care of their babies and do not feed them, and eventually they die. In three of the clinics, pregnant women are not followed in collaboration with radiologists, the professionals claiming that they are experienced enough to monitor these women within their own disciplines. Only one of them collaborates with the radiologists and on their clinical committee the radiologist is a regular member.

In three hospitals, abortion on demand is performed in the first 10 weeks of pregnancy according to the wishes of the parents and the limitations of the relevant legislation. In one hospital, abortion on demand up to the 10th week is not carried out as a clinical decision, although it is legally permissible.

If a pregnant woman wants to give birth to a fetus with a known congenital malformation, all of the clinics declare that they respect her decision. Only in one hospital is a psychiatric consultation requested if there are suspicions about the woman's decision.

Professional training in ethical decision making

None of the clinics have programs available to counteract burn-out in health care professionals, who are not trained to challenge their own values. Staff physicians do not include nurses in decision-making processes and nurses also claim that they do not take part. Both physicians and nurses recognize this as an important problem. The physicians did not even mention the roles of nurses and, when asked, they claimed that nurses are not trained sufficiently in ethical approaches to allow them to take part in decision making and academic activities.

In one hospital, staff do not follow any specific codes of ethics; they sometimes use the guidelines of the Royal College of Physicians, London, and their own clinical protocols. In all the other clinics, legal rules dominate the decisions made.

In the *in-vitro* fertilization clinics in one hospital, for reasons of procreative beneficence, there is a consensus that embryos that may be carriers of, or are shown to have autosomal recessive conditions such as thalassemia, are not implanted. There are future plans to prevent genetic diseases but they do not want this to be abused by the mistaken beliefs and irrational desires of both health care professionals and families. Others do not have a specific consensus decision on this issue.

Priority issues and ethical questions

An example of case histories that were still remembered by the participating professionals was an anencephalic baby whose mother believed that the head would grow to a normal size after she was born. The professionals waited until she gave birth (respecting her autonomy), but the baby died a few days later. Some

families prefer to give birth to babies with metabolic disorders and their autonomy is respected.

Some of the children discussed are still alive and the families are happy. In two of the institutions, the physicians usually try to inform the families about the risks to the best of their ability, but they choose to go against the parents' decision only when the mother's health is in danger. They admitted that they learn much from the patients and, when they could not decide, parents would make decisions based on common sense. In one of the units, an anencephalic baby made terrible and distressing sounds. The health care professionals decided not to continue treatment and, by consensus clinical decision, stopped feeding. After the baby's death, the mother suffered profound depression and, later, the nurse concerned had a reactive depression and some other nurses wanted to resign. They organized a clinical meeting and reached a consensus decision not to stop essential care of babies, even those with irreversible severe malformations. In one of the institutions, a pregnant woman was diagnosed at 21–22 weeks of pregnancy with a fetus with symmetrical growth retardation. The amniocentesis result was normal but the retardation continued. In the 24th week abortion was offered to the parents. They refused but, in the 29th or 30th week, the fetus died. The clinicians in charge were not sure that their decision was satisfactory but it was based on respecting the mother's decision.

To summarize (Table 1), the three questions in the first part were 80–100% answered negatively by mentioning that there was no institutional ethics committees, guidelines or protocols.

Question 6 in the second part controlled involvement of the professionals in a positive way: 80% of the respondents mentioned that they do not follow international codes of ethics, as they did when answering the first part of the questionnaire.

Question 4 about abortion in the institution showed 80% declaring that abortion takes place, but, even when it does not, 20% are regulated by legislation or the organization, not by codes of ethics.

For questions 1 and 2 (decision-making protocols) 100% of the respondents declared that there are individual ethical considerations such as the sacredness of life and respect for life.

Questions 5, 8 and 9 indicate that individual respect for both autonomy and beneficence was shown by 64–100% of the physicians and nurses, but 80% stated that there is not an institutional ethical approach to procreative choice and beneficence in *in-vitro* fertilization units. The institutional ethical basis for questioning against bias or conflict of values is not met because there are no clinical ethics committees and the physicians are not used to resolving ethical dilemmas.

Questions 3 and 7 (professional training in ethical decision making) explored interdisciplinary collaboration, the roles of health care professionals and ethics education of caregivers for the beneficence of both professionals (against burn-out or serious stress) and patients. The answers do not show any positive approaches.

Since there was no relevant institutional ethics committees, we could not obtain permission for our study. Therefore, although we mention some patients, we have avoided providing any identification, or private or specific information. We have also preferred not to name the institutions.

Discussion

Ethical decision making about fetuses with an NTD and examples of institutional ethical approaches

Life-threatening NTDs represent a wide spectrum, from a single defect with an extremely poor prognosis such as anencephaly to a lesion with long-term developmental implications such as meningomyelocele (SB). The affected fetus and the newborn baby present a special dilemma for the health care teams and families.

One or both parents may exercise their autonomy during the decision-making process about a fetus or infant with an NTD and may feel guilty about the defect, the likelihood of the child having an abnormal appearance, or the prognosis of some degree of continuing disability. Physicians may prefer to use current technological methods for the beneficence of the fetus or the child, or to satisfy a research interest of their profession, as with the transplantation of the organs of a newborn anencephalic child, or try to reassure themselves about the child's quality of life or best interests.[13,16,45]

In the clinical setting, most critically ill babies would benefit significantly from the development of a prospective plan of care, together with a robust decision-making process that includes the ethical implications. This should be a process in which the clinical team at a tertiary care center and all those involved with the care of the child, including physicians, nurses, consultants, social workers, residents and the family, would consider systematically all the important issues when making critical decisions related to the child's care.

In the USA, decision making about affected fetuses or newborn infants and, more recently, about critically ill older children, has evolved dramatically over the last 20 years while under some unusual pressures.[45] Reflection and the evaluation of past mistakes has benefited individual decision makers and society. Because of the relative frequency and complexity of these issues, it has been proposed that health care professionals should develop a prospective plan of care that addresses current and potential ethical concerns.[45]

This topic has legislative, religious, moral and medical implications for decision makers. Islam does not permit abortion unless there is a health problem with the fetus or the mother. In Christianity, abortion is not permitted unless there is a health problem and Judaism allows abortion only when there is a health problem with the mother.[23,24,47] Detailed studies of religious approaches have been carried out, but these are not of concern here.

Fetuses with NTDs are discussed ethically from the point of view of the life of third parties, and proxy consent is needed for decisions. In some studies it has been proposed that children have no history of preferences on which to base a surrogate judgment and such judgments for minors must adhere to the best interest standard.[13] These third parties have the potential for life, but the question of their being a 'person' is still an unresolved issue. According to Beauchamp and Childress[48] the autonomy of the mother, the fetus's right to life and the physician's principle of beneficence are the major issues that are in ethical conflict. In the context of both medical and ethical approaches, 0–10 weeks of pregnancy are declared as acceptable for abortion, but 10–24 weeks of pregnancy is negotiable for abortion because there is the belief that a fetus of this gestation has become a person and abortion may therefore imply killing an

innocent third party. After 24 weeks, abortion is usually not chosen because the fetus could live after the intervention. The moral decision-making process is usually complex. The pertinent factors are the uncertainty of making proxy decisions for incompetent patients who have never been competent, the degree of emotional stress on parents, the moral status of the infant, serious time constraints, conflicts of interest (between parents and child, physician and child, parents and physician), the difficulty of predicting future handicaps, the inadequate communication of information between members of the health care team, and the logistical problems inherent in using hospital committees or the law.[49]

Physicians, nurses and other professionals who care for children have traditionally seen themselves as advocates for their patients. Ramsey[50] is convinced that neither parents nor physicians are the best proxies. Instead, he suggests a disinterested party such as a hospital- or unit-based committee. Many hospitals set up such committees, not as decision-making bodies, but with advisory or review responsibilities. They may be useful when there is conflict among the decision makers or when parties request outside assistance.[45]

What criteria should be used as a basis for decision making for affected fetuses or newborn babies? Should any consideration be given to medical indications, quality of life, technical medical criteria, nonmaleficence/best interest, economic factors, certainity/uncertainty, waiting until certain, statistical prognosis, using available data, the present condition, or benefit–burden analysis?

Are institutional ethics committees helpful? What are the roles of health care professionals?[13–16,45,51]

All cases of SB raise serious medical and ethical questions to be resolved between the mother, the fetus and health care professionals. Institutional ethical frameworks and professional multidisciplinary teamwork may make some contribution to the decisions of all parties. Throughout history, different moral theories have been taken into account,[12,15,16] as well as principles or concepts that provide some basis for decisions. Abortion, the beginning of life, euthanasia, the artificial maintenance of life and other topics are frequently discussed. Evaluation of medical situations and clinical ethics are practical disciplines that provide a structured approach to assist physicians in identifying, analyzing and resolving ethical issues in clinical medicine. Occasionally, physicians and patients may disagree about values or face choices that challenge their values. It is then that ethical problems arise. Weighing absolute truth and best interests are important in the application of ethics.[12–16,45] A third normative dimension is usually present in clinical decisions but the inherently ethical aspect of such decisions may not be appreciated in medical contexts because such decisions are considered to be medical rather than moral.[14]

In some of the composite cases presented in Jonsen *et al.*,[13] it is proposed that, if parents refuse treatment for babies with an NTD who have a combination of extreme painful and mental disabilities that could lead to a quality of life that can be judged as undesirable by any human being, the parents' decision could be accepted as ethically justified. The same decision cannot be justified if made on grounds of the welfare of the family or of other children in the family. Nevertheless, these are additional considerations, which, while not decisive, deserve attention and may become decisive. The transplantation of fetal tissue from anencephalic babies for research can be justified only if there is no direct connection between the abortion and obtaining the

tissue, maternal consent is obtained, and a research protocol is approved by a local institutional review board.[13]

Studies have revealed that physicians are no freer of bias against certain life-styles than the general population, and disabled people are also exposed to life-style bias.[13]

Concerning a case involving the withholding of surgery from a newborn baby with SB and other complications, New York's 'Baby Jane Doe' (which was a turning point in the history of ethical dilemmas for critically ill infants), Freeman[52] discusses that standard ethical approaches to decision-making based on rights, duties, obligations, beneficence or best interests may seem inadequate when applied to individual infants. It is also reported that a process that takes account of moral theory, but which allows tolerance, within limits, for a possible range of decisions, would appear to offer more reasonable decisions. On the other hand, a working group[53] emphasized that, since medical, psychological and social considerations have to be 'more complex and less clearcut', judgments regarding treatment should be made on a case-by-case basis.

Bliton[54] presented a study on ethical concepts relevant to intrauterine treatment and report the ethical significance of a moral belief common among pregnant women who seek intrauterine interventions, namely that their fetuses are already 'babies'. It is emphasized in the same study that, being sensitive to a pregnant woman's vulnerability to her own beliefs regarding potential disabilities, the intervention and its potential outcome should be evaluated. Lyerly and Mahowald[55] discuss the critical subject of 'fallacy of abstraction', which implies trying to separate interests of the fetus and the mother that are not in fact separable. These authors review the rationale for the essential tie between the fetus and the pregnant woman. When surgery is performed on pregnant women for the sake of the fetus, it is incomplete to discuss this in terms of the fetus alone. The concept of 'equipoise', which is the state of uncertainty about the risks and benefits of alternative interventions and nonintervention, is another ethical difficulty.[55,56] Such explicit discussions are ethically important to safeguard against the judgments, enthusiasms and biases of health care professionals.

An important clinical uncertainty operates when chronic, nonurgent and irreversible conditions such as newborns and fetuses with defects require onerous treatment, when ethical problems and ethically justified decisions will come to the fore. On an individual level, emotions that a physician may be unwilling to admit may outwardly affect his or her 'objective' judgments: anxiety or fear regarding death and disability, dislike of certain types of people or a life-styles, racial prejudice, repugnance for older or mentally disabled people, or a desire for economic profit. Clinical biostatistics, clinical epidemiology, and ethical decision-making analysis can be utilized to evaluate physicians' decisions and patients' outcomes by the deliberations of a multidisciplinary ethics committee. The formulation of clinical judgments takes place by gathering and interpreting data in a complex context of scientific and personal assumptions. The clinical recommendations often reflect individual physicians' attitudes about risk avoidance, enthusiasm for intervention, and other personal and professional values.[12–16] It has been recommended by different authorities[13,45] that, for healthy and deliberated decisions, individual approaches could be discussed at multidisciplinary committee level, where reflections on a societal level may be analyzed through the results of detailed and large-scale prospective or retrospective cohort studies.[13–16,45] In this way, the 'uncertainity', the 'probability' and the decisions have a chance to be reviewed objectively by parties that are not involved in the emotional stresses.

Examples of institutional ethical approaches

In an educational program for medical school students in Newcastle, UK,[57] medical ethics is introduced as part of a human behavior course. These students are introduced to patients at the very beginning of their medical education so that they become sensitized to patients as people rather than as vehicles of disease. One important question for them is to decide about a newborn baby with SB. The outcome is that the students' views of right and wrong alter and mature as they are encouraged to think about ethics and look beyond traditional answers.

A study from India[58] reports that, because SB requires multidisciplinary attention, the ultimate goal is prevention, co-ordinated efforts to establish antenatal diagnosis, screening tests for this anomaly, and solving the difficulties faced by these children at home and in school. Such responsibilities can be undertaken only if a group of doctors, nurses, social workers, administrators and philanthropists are dedicated to the well-being of these children. A special clinic in India helps to maintain such a group in order to provide for all the medicosocial needs of SB patients under one roof.[58]

Ethics committees have been established since the 1970s. Today, in the USA, more than 80–90% of hospitals have ethics committees.[45] Chervenak and McCullough from Cornell University, New York,[59] report that the staff provide an ethical framework that identifies criteria for fetal surgery and establishes a standard of care, describes an appropriate informed consent process, considers whether selection criteria should include the abortion preferences of the pregnant woman, and examines whether physicians have an obligation to offer referral for investigation. Cornell University is an example of how an institutional ethics framework operates. This university has a 20-year history of collaborative research on ethics in fetal diagnosis based on the concept of the fetus as a patient.[60] The same institution proposes that ethics is an essential dimension of the clinical management of pregnancy complicated by fetal anomaly.

In Turkey, the majority of hospitals have an institutional review board, but this research shows that the units studied in four tertiary-care centers, when resolving ethical dilemmas, do not seek ethics consultations and do not have the relevant ethics committees. Health care professionals usually explain their personal considerations as focused on respecting family decisions and informing parents, but it has not been traditional to consider ethical principles as protocols.

The role of nurses

Currently, on taking a global perspective, physicians and patients have various responsibilities and obligations to the wider world in which their relationship takes place: they have families, live in social and political communities, and are employed by or have a contract with health care organizations. The patient–physician encounter now takes place in more complex institutional and economic conditions than ever before; only occasionally does the traditional private relationship exist. Today, more often doctors stand in multiple relationships with other physicians, nurses and allied health professionals, health care administrators, third-party payers, and professional organizations, in addition to patients and their families.[13] It is proposed by Jonsen *et al*.[13] and by other authors[16,45] that clinical ethics relies upon the conviction that, even when perplexity is great and emotions run high, physicians and nurses can work

constructively to identify, analyze, and resolve many of the ethical problems that arise in clinical medicine.[13,16,45] Fostering ethical competency in health care professionals is an ongoing staff development process that encourages professional growth and staff satisfaction. Andrews reports[61] that the successful application of ethical decision-making skills is integral to the modern practice of nursing and nurse satisfaction. A descriptive study[62] explored the experiences and attitudes of 75 nurses who gave direct care to anencephalic infants. One ethical issue for a majority of the nurses was concern about whether the clinical treatment protocol, or the protocol for care or the approach to be used after death, considered the dignity of the infant. Other concerns were whether the infants felt pain and their physiological responses. In part of another detailed investigation,[63] the attitudes and perceptions of nurses who were ordered to provide long-term care for a female child with anencephaly were investigated. The nurses experienced stress and suffering when they cared for critically ill and dying patients. Moral distress occurred when they were unable to translate their moral choices into moral actions. The nurses simply put on a professional face and continued to provide care to compensate for feelings of powerlessness. They felt guilty and angry and believed they were not included in the decision making. They concluded that suffering among caregivers does occur and measures must be taken to reduce the stress of health care professionals as they provide care to patients who cannot recover, and that guidance must be provided to health care professionals, especially concerning the care of such patients.[63] It is claimed in another study[64] that pediatric rehabilitation nurses are expected to develop partnerships with parents; they should serve as family consultants, not as directors of children's care. Nurses are also proposed to play a crucial role in the timely presentation and dissemination of accurate information to women of childbearing age and other professionals on the benefits and limitations of screening.[65,66] To take an active role in the regulation and formation of health policies should be a fundamental responsibility of the nursing profession.[67] A Dutch study proposed that, for healthier preconception care that has ethical components such as risk assessment, health promotion and disease prevention, primary health care professionals should be involved, as well as gynecologists, midwives, nurses, clinical geneticists and genetic counselors.[68]

The health problems of children with meningomyelocele compromise the psychological status of their mothers as their main carers and the problems of the social networks involved in their care. The psychology of pregnant women is crucially important because, if abortion is preferred in very late pregnancies, mothers are at risk of serious depression. If they give birth and see the baby, then the mother's approach to the disability may be more realistic. The critical point is to raise awareness about the problems. A study from Manchester, UK, showed the importance of education for health care professionals on the significance of the perceived stress of carers and suggested ways to reduce psychosocial morbidity.[69] A study from the USA reported that parents of adolescents with SB face unique challenges and it was proposed that rehabilitation services with a major role for nurses should provide guidance to foster autonomy, decision making, and cognitive and coping skill building to help both parents and adolescents.[70] In the UK, young adults with SB expressed a particular need for community nurses.[71]

Other discussion points are the status of disabled children in society and their care. One study reported[72] that mothers are more likely to be overprotective than fathers. Parental overprotectiveness was associated with lower levels of pre-adolescent

decision-making autonomy as well as with parents being less willing to grant autonomy to their offspring in the future. Another study from the USA reported on the experience of mothers of children with SB who were between the ages of 12 and 18 years and revealed a constitutive pattern of always being worried about their children, always treating them differently to normal children, and maintaining the struggle for them. It was proposed that nurses can use narratives to create supportive relationships with mothers, extending their understanding of these women.[73] Older mothers (aged over 35 years) and mothers with school-age children may need more resources than current social support systems typically provide, according to the results of a study carried out in South Carolina.[74]

Conclusion and suggestions

The story of fetuses with an NTD starts with preconception prevention, proceeds to their care as adolescents, and also touches on civil rights. Decision making starts with proxy consent shaping the complicated issues of medical and clinical ethics and social networks. The topic offers different reflections from culture to culture; however, there are some common global messages.

Fetuses with NTDs present one of the most complicated issues of medical ethics. There are social, economic, moral and religious implications in addition to the medical aspects. Preconception preventive measures, diagnostic tools, abortion, surgical interventions after birth, and expectations from life, all need detailed and cautious decision-making processes.

In Turkey, we observe that major perinatology units do not have an ethical framework or ethics committees, and that health care professionals usually face difficulties. Most of them, especially nurses, complain about the stresses they experience when dealing with such patients, both in Turkey and in other parts of the world.

When health care professionals have to take care of patients with irreversible or complicated conditions, they prefer to reflect their moral thoughts in moral actions. If they do not have a professional ethics framework, decision-making protocols or the specific education required to evaluate these problems, when nurses especially are not involved in the decision-making process, they suffer from stress and experience burn-out symptoms.

In some perinatology centers in Turkey ethics-based approaches are used, but we can conclude that they are not at institutional level, but rather commonsense approaches at individual level.

Nurses seem to have a secondary or indirect role in the decision-making processes in such centers in Turkey and in some other countries we have discussed, but they are responsible for the care of these patients. For those such as fetuses with an NTD, ethics education of health care professionals (including an important role for nurses in improved programs and curricula), and professional approaches such as ethics consultation services or hospital ethics committees could be helpful.

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