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## Panel Discussion

### End-of-Life Issues at the Beginning of Life

**Moderator:**

*Tanveer Mir, MD, MACP  
Associate Chief, Geriatrics and Palliative Medicine  
Long Island Jewish Medical Center  
North Shore Long Island Jewish Health System  
New York, New York*

**Panelists:**

*Hossam E. Fadel, MD, PhD, FACOG  
Maternal Fetal Medicine, University Hospital  
Clinical Professor  
Department of Obstetrics and Gynecology  
Medical College of Georgia  
Augusta, Georgia*

*Ali M. Nadroo, MD, FAAP  
Assistant Professor of Clinical Pediatrics  
Weill Medical College of Cornell University New York  
Associate Director of Neonatal Intensive Care Unit  
Associate Program director Pediatrics  
New York Methodist Hospital  
New York, New York*

*Malika Haque, MD, FAAP  
Clinical Professor of Pediatrics  
College of Medicine, The Ohio State University  
Pediatrician, Nationwide Children's Hospital  
Pediatric Consultant  
Bureau of Disability and Social Security  
Medical Director  
Noor Community Free Clinic  
Columbus, Ohio*



## Discussion

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**Dr. Skina Fadel:** *How would you counsel a woman found to be carrying conjoined twins?*

**Dr. Fadel's response:** Conjoined twins is a serious problem, and it is also very variable one. There are many different degrees of conjoined twins. Some of them can be easily separated, while others are very difficult or impossible to separate. Success depends on the particular way they are conjoined; therefore, there is no one answer to this question. Successful separation depends on the extent of fusion and which organs are shared. For example, is it the heart

that is shared? Is it the liver? If the twins do not share vital organs and their case seems to be operable after delivery, that is very good. But if it seems from the imaging studies – ultrasound or an MRI that the twins cannot be separated, then this will be like addressing a lethal malformation, and you have to deal with it depending on the gestational age and other factors. One may counsel termination of pregnancy or offer palliative care.

**Question from the Audience:**

*This is a question to the whole panel. In India, when we were young doctors, we did not have priests or mullahs or imams in our hospital, and doctors advised the patient. When we came to this country, we had a chaplain, a rabbi,*

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and now a Muslim imam. With the rising cost of health care, this is an extra burden on society. Now, residents and young doctors are trained in cultural anthropology; they know a little bit about Judaism, Christianity, and Islam. They can convey their compassion directly to the patient without the intervening clergy. Muslims do not need an intermediary between themselves and God. The patient or family members can pray and read the Qur'an. If the doctor is a Muslim, he or she can read the Qur'an and pray for the patient and talk to the family. Because the United States is a world leader, its prominence can cause the same trend to replicate in India, Pakistan, and elsewhere. It is an additional burden basically. Is the cost of clergy in the healthcare team worthwhile?

**Dr. Mir's response:** The truth is that the most successful models in health care are those that involve other health professionals and a chaplain or clergy. For those of us who are involved in day to day workings of the hospital, we know that we cannot succeed alone as physicians unless we have the backup of nurses, social workers, and the other professionals behind the scenes. Spiritual care is a very important part. Also, it is a requirement of the joint commission, the Accreditation Council for Graduate Medical Education (ACGME), which requires us to teach our residents and students in cultural and religious affairs. Therefore, I do not think the team approach is going away from medicine.

**Dr. Nadroo's response:** I know we all come from different cultural backgrounds and that very limited resources are allocated to health care in countries such as India and Pakistan because there are other basic needs of day to day life, such as food and roads and medicine. So, yes, resources have not been expanded to include the clergy, but there is an equivalent system going on in those cultures. They do not have psychiatrists and psychologists evaluating the population, but there are babas and saints who do part of the job. Somebody falls sick, he does not go to the doctor, he goes to a saint, a religious person, and then that person blows on the water and gives it to that person. Therefore, there are certain things in culture that are different. In this country, we are talking about the additional cost for health care issues. I mentioned that the viability definition changed from 32 weeks to 23 weeks. There was a cost involved in reducing neonatal mortality. In addition to the technical advances that enabled this decrease in the gestational age of viability, there is another

cost to improve mental and spiritual health. In the United States there are different cultural and ethnic backgrounds, and these different groups have different demands. Avoiding the conflicts that will arise and the problems that will be created justify the additional costs.

**Dr. Haque's response:** When I first started my residency we did not have any of this, but as we went along we realized that there was a need. Just imagine the psychological breakdowns that these families could face from the inadequacy of care after their traumatic experiences if these services are not in place. This potential for lifelong trauma could be reduced at an early stage with the intervention of an imam, clergy or social worker. We appreciate what you are saying, but at the same time I think the needs we have realized have increased, and this is more of a comprehensive type of model right now. Moreover The Joint Commission Of Hospitals requires a multi disciplinary approach in cases with the end of life issues and cases with similar complex problems.

**Question from the Audience:**

*I would like to thank the panel for bringing us up to date on some of the growing ethical challenges. My question is directed to Dr. Haque. Has there been any change in policy over your years of practice with respect to showing parents their severely malformed newborn who is not expected to live? I am asking this only because I had an incident in a city hospital where an anencephalic baby was born, and the parents were not shown the baby and were told the child had died. Was that just an exception where I was or has there been a change?*

**Dr. Haque's response:** As far as I know there is no policy as such. Parents have every right to see their newborn and mourn its loss. Maybe the doctor felt at that time because of the parents' poor emotional state that he could make the decision. There are no such rules, regulations or policies that prevent the parents from seeing their deformed child.

**Dr. Fadel's response:** Unfortunately, 30 years ago as you said, physicians generally felt that mothers or parents would not like to see a deformed child, but we do definitely realize now that this is not the case. Actually, it is always better for the parents to have the baby and hold him or her. In fact, we encourage parents to give the baby a name, take pictures, and maybe keep a lock of hair. Otherwise, they will always have nightmares and imagine that the child

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looked worse than he or she actually did. Even if it does have external malformations, the parents will always imagine that it was worse. We now believe that seeing the baby is much better for the grieving process.

**Dr. Mir's comment:** I could just point out a brief comment relating to adult medicine. There was an article in the Journal of Critical Care Medicine that showed if the families were allowed to be in the room when cardiopulmonary resuscitation (CPR) was provided, most of them would have not pursued CPR because they saw how traumatic and violating it was for the patient. Now I think that, if it is not too much of an emotional burden for the patient's family, they should be allowed in the room during CPR.

**Dr. Arfa Khan:** *Thank you all for nice presentations. If a pregnant woman had an amniocentesis and was found to be carrying a fetus with Down syndrome, she could legally have an abortion. I would like to know the viewpoints of the different religions. Is the amniocentesis usually done at 18 weeks?*

**Dr. Fadel's response:** Actually it is done earlier most of the time, usually at 14 to 16 weeks. The predominant Islamic view is that you do not terminate the pregnancy for Down syndrome, as it is not lethal. Some scholars will allow termination of pregnancy (TOP) if there are other associated significant fetal abnormalities, such as complex heart defects and other scholars would allow it as long as it is performed within 120 days of conception, or approximately 19 menstrual weeks. I think in the Catholic faith, it is completely forbidden. I also think the majority of Protestant denominations would allow abortion for cases of Down syndrome, but not the evangelicals. I think in Judaism, they would allow the pregnant woman with a Down syndrome fetus to have an abortion. That is my understanding, but obviously I cannot speak for them or other religious groups.

**Dr. Nadroo's response:** Down syndrome patients can live 40 years or more. They can be fairly independent and take care of themselves. God created humans with a spectrum of different levels of intelligence. Down syndrome individuals would be in the lower end of the spectrum and the super duper

intelligent individuals are on the other end, so aborting Down syndrome fetuses would amount to killing an individual, and it would not be allowed. It would only be permissible if there is danger to the mother because of the pregnancy. Down syndrome fetuses do not pose any danger to the mother. As far as Catholics are concerned I am not a scholar, but in the gospels I read that the embryo is an individual no matter how small. Pope John Paul II has said this. This means that it does not matter whether or not the fetus has Down syndrome. The embryo is an individual by itself, and it has life.

**Dr. Haque's response:** Down syndrome children grow up to be adults. In fact, I have taken care of several Down syndrome babies, children and adolescents. They range from mild to moderate mental retardation. There are Down syndrome clinics in most pediatric hospitals. The National Down Syndrome Society assists in the better management of children and adults with Down syndrome. They can be engaged in workshops and vocational training, and they could work under some supervision and make their own living. They are very happy kids. I do not know how many people have had the occasion to know or spend time with children with Down syndrome. I had a friend of mine who had a baby with Down syndrome who lived to be 32 years of age. He had an atrio ventricular septal defect, and the family declined any intervention. This child was the happiest child I have ever met. I remember taking care of him at the hospital, and we had to give him IV because he was dehydrated. He remembers that all the time. At any get together he would try to find me and say "Dr. Haque IV, Dr. Haque IV," pointing to his hand. I said, "If I ever get lost, send him to find me, and he will find me." So they are very adorable people with happy disposition. They can live long depending on the Medical care they receive and they leave a lot of good memories behind. Under supervision, they could be useful members of society.

**Dr. Mir's response:** We see Down syndrome patients in their 40s and 50s who have geriatric syndromes. They tend to live longer now than they they did before. They do very well unless there is a very serious associated congenital heart defect such as tetralogy of Fallot. Thank you for this session.