

CONTENDING MODERNITIES

The Ethics Debate Transcript

A Contending Modernities Podcast Science and the Human Person Working Group

EHSAN MASOOD: “Hello, 67 years ago, a 49-year old woman named Ruth Tucker received a kidney transplant in a pioneering operation in a pioneering operation in Evergreen Park Illinois, here in the United States. The transplanted kidney survived only 10 months, but it gave Ruth Tucker’s own kidneys time to recover, and it meant that she would live for a further five years. Five years that she probably wouldn’t have had without the transplanted kidney. Today it seems hard to imagine life without being able to swap kidneys, hearts, pancreas, and lungs. The list of organs that can be routinely exchanged is getting longer. These procedures represent a huge leap forward for medicine, but they don’t exist in a vacuum. The decision to donate, or to accept a new organ, can often involve an array of people. There are family members, medical experts, lawyers, religious leaders, and of course, the individual who might be giving or receiving an organ. Each has a voice. Sometimes a transplant cannot occur until a consensus can be found. My name is Ehsan Masood, and I am a science journalist based in the UK. In this podcast, we are going to simulate how decisions will be made in one transplant scenario involving a Muslim family. They are the mother and the father of a 14-year old girl. Let’s call her Sara. Sara is on life support, with severe brain injuries. Sadly, she is unlikely to live, and the family must decide whether to donate her organs. The decision is made more complicated by the fact that mother and father come from different Islamic traditions. The father follows a branch of the minority but sometimes more liberal Shia tradition; the mother on the other hand is from a branch of the majority Sunni tradition.

“We are going to explore the issue with representatives of some of those who would, in real life, be making decisions on whether or not to donate. Playing the role of family representative, Najah Bazy, and in the role of healthcare systems representative, Hasan Shanawani. We are also joined in the studio by three experts, expert commentators in the field of religion and bioethics. They are Asim Padela, who is a medic, hello Asim.”

ASIM PADELA: “Good morning.”

EHSAN MASOOD: “Abdulaziz Sachedina from George Mason University who studies bioethics and Islam.”

ABDULAZIZ SACHEDINA: “Hello everybody.”

EHSAN MASOOD: “And we have Robert Tappan from Towson University who studies reproductive technologies in Iran.”

ROBERT TAPPAN: “Thanks for having me.”

EHSAN MASOOD: “Welcome Robert. Very briefly, panel, from our expert panel, could you maybe begin with a very short statement of where you think the family should go next. Starting with you, Abdulaziz.”

ABDULAZIZ SACHEDINA: “I think a very important issue that underlines the decision to donate the organs of the brain-dead person is actually the definition of death itself; whether it is acceptable in a particular school of thought and whether they would submit to the physician’s statement that the person is brain dead. That would then allow the family to decide if they can donate organs.”

EHSAN MASOOD: “So in a sense what you are saying is that if Sara has indeed died, then the debate begins about the acceptability or not but it is about defining death first.”

ABDULAZIZ SACHEDINA: “Exactly. A very important issue is how do we define death. Because in the traditional explanation of death we are talking about the death of the heart, so to speak, the heart stops beating. That was the criterion that was used in the traditional definition of death. But the brain death, the heart could be moving because there is a ventilator connected to the heart. So that is why we find that there is a question mark in front of the brain death. Who accepts that criterion, who doesn’t.”

EHSAN MASOOD: “Thank you. Asim.”

ASIM PADELA: “So, what I heard from the case, however, is that a loved one is severely brain injured. So I haven’t heard that she is even thought to be dead at this point. So where the family should go is to think about what the situation is for them. If you are parents you know that if your child has severely compromised neurological status, how you would feel. Where are they? We should be thinking about, as physicians, helping them realize where they are in their situation. I

would advise them to take some time, to pause, to think about their daughter, to think about what the situation is, to get some data points from the physicians and from some other counselors that are in the hospital. And then we can talk about whatever else will happen. You have to understand their tragedy first.”

EHSAN MASOOD: “Robert.”

ROBERT TAPPAN: “And part of this idea about brain death is, in terms of religious sensibilities, is that death is, in the Islamic tradition, something to do with the soul leaving the body. And that is not a scientifically provable idea. So how do you, can you relate the death of a person, whether that is brain death or cardiorespiratory death, with the departure of the soul. And brain dead patients kept on ventilators don’t seem to be in that condition of somebody whose soul has left.”

EHSAN MASOOD: “Very briefly, Asim.”

ASIM PADELA: “I also want, as someone who is a medic, we are using a term, brain death, that doesn’t exist. It’s a misnomer. There is no such thing as brain death, there is no brain dead. We adopt criteria: do I think that the person is not going to return to a conscious status.”

EHSAN MASOOD: “Let’s run through what actually happened to Sarah. At ten to eight this morning, Sara ran out of her house towards the school bus. The bus was waiting on the other side of the road. She was excited to see a friend waving, but in that excitement, Sara failed to check the road properly. And as the teenager emerged from between two parked cars, she was hit by a truck. The driver didn’t have a chance. It was a tragic accident. Sara was rushed to hospital, the emergency team did all they could, but to no avail. She was declared dead shortly after 10 o’clock. Both the mother and the father were at her bedside when a representative of the hospital approaches them, and asks if he would have a word in private. Would they, he says, consider donating their daughter’s organs. Hasan Shanawani, you’re representing the hospital. Can you tell us about Sara’s medical condition, and also, enlighten us a little bit about Asim’s point about the discussion on brain death.”

HASAN SHANAWANI: “So, to be precise, in most places in the United States actually the process of introducing the possibility or organ donation would not be done by a hospital staff member. In fact, it’s done by a separate agency that is sponsored by the state.”

EHSAN MASOOD: “What is the name of the agency?”

HASAN SHANAWANI: “It literally varies from state to state. In the state where I practice and work it is called ‘Gift of Life of Michigan.’”

EHSAN MASOOD: “And it is a state agency?”

HASAN SHANAWANI: “It is a private organization, some are for profit, some are not for profit, and they are licensed with the organization and they generate their revenue from the organ donation process. So I would actually not be a hospital representative in most instances. The hospital representative typically will have told Sara’s family of the situation, of the tragedy, they will probably have introduced them to an idea that another clinician, typically a nurse, will come to the bedside to introduce the subject. And it is at that point in time that that entire conversation is taken over by the organ transplant organization.”

EHSAN MASOOD: “Thank you. We will come back to you in a sec. Najah Bazy. Najah, you are a consultant nurse, and you work in these sorts of situations in cross-cultural settings. You are representing the family. Can you lay out who the parents are and how do you think their beliefs would influence the choices that they have to make coming from these two traditions?”

NAJAH BAZZY: “So, just to clarify, I am a clinical transcultural specialist. The clinical piece is important. From my perspective, I am neither going to advocate a hospital’s position, nor the organ donation gift of life position. I would be strictly working with the family to understand how they are feeling, and to give them a space, a very safe space to be able to think through not just organ donation but also to deal with the tragedy and the grief on hand. So, it’s important, from my perspective, to be able to allow this grieving family the respect and the dignity that is required for any family without the imposition of someone knocking on the door to ask this very difficult question. I would look for the subtleties in the way in which the question is asked so that I can determine the context. So often times it may be said that this is an opportunity to have your child live on in a legacy that could be wonderful and beautiful. My role is to find out whether or not the family is even interested, in their grief, in that legacy dimension. They may not be there, they may not ever want to be there.”

EHSAN MASOOD: “But they don’t have a lot of time, do they.”

NAJAH BAZZY: “They don’t. Well, depending on what state you are in. For most states, once brain death, if that is what we are going to call it, for the sake of the conversation, is declared, there is usually 24 hours to remove the ventilator. However, when organ procurement is something that could be interesting to the family, then we tend to make the length of the time longer to allow the family to digest the idea which is interesting in and of itself. So in terms of the family, I would be assessing the religiosity of the family. And to take away the labels. Because just because someone is Muslim doesn’t mean they are an adherent Muslim. Just because they might be of the Sunni sect or Shia sect does not mean that they themselves are interested in knowing what those rulings are. So I am there to guide the conversation by listening a lot and being an advocate for the family. Lastly, there is the difficult piece, which is that as Muslims we need to bury before the next sunset. So there is the urgency. Muslims need to navigate those stages of grief so quickly, and what does that do to the family.”

EHSAN MASOOD: “So you have mentioned the theology. Let’s move to our theological experts. Robert, I would like to start with you. If you could put yourself in the shoes of the father, who comes from a Shia tradition, what would be the bounds of acceptability in Shia theology when it comes to questions such as these.”

ROBERT TAPPAN: “Sure. You know, there are some parameters and things to keep in mind, as Najah said, for example, we might assume, and perhaps if I was this Shia father and this was on the table and I had to consider it I would consult with my marjah, with the scholar that I follow. Ayatollah somebody.”

EHSAN MASOOD: “This is a religious leader.”

ROBERT TAPPAN: “That’s right. One of the grand ayatollahs, as they are known, high ranking scholars. I don’t know that is always going to be what somebody does. Because again, we don’t want to say whether somebody is Sunni or Shia this is simply a religious thing: I just look at the book and it tells me what to do; get the ruling of the scholar and it tells me what to do. All those issues of family concern, care for your loved one, all of those things will come into play. But I think that would be the first step, to consult with one of those leaders.”

EHSAN MASOOD: “And what would one of those scholars from the Shia tradition advise the father? What would they say?”

ROBERT TAPPAN: “It’s really going to depend. This is the thing with the Shia leadership, is that there is a hierarchy of sorts but there is no papal figure.”

EHSAN MASOOD: “So what you are saying is that even within Shiism there is a spectrum of views.”

ROBERT TAPPAN: “Oh, absolutely.”

EHSAN MASOOD: “And could you just perhaps just chalk what that spectrum might be?”

ROBERT TAPPAN: “Sure, and I might defer to Professor Sachedina—“

EHSAN MASOOD: “We will come to Professor Sachedina in a minute.”

ROBERT TAPPAN: “—but you can see in Iran there is actually a government law that permits cadaveric donation from brain dead patients. So it is really going to depend. You might have that, or you might have a prohibitive stance as well.”

EHSAN MASOOD: “This government law, does that have a theological underpinning or is it just a law of the state?”

ROBERT TAPPAN: “That’s right, it does have a theological underpinning. Any state, civil, law has to be approved by religious scholars.”

EHSAN MASOOD: “What is the theological basis of that law that allows cadaveric donation?”

ROBERT TAPPAN: “You know, in the case of Iran, I am not sure if it is based on public interest—“

ABDULAZIZ SACHEDINA: “It is monetary advantage that one can derive from organ donation. I think there is a worry that—“

EHSAN MASOOD: “Just to unpack that, what is monetary advantage?”

ABDULAZIZ SACHEDINA: “It means I could sell my kidney for a certain amount. I could also charge someone to receive a cornea, for example, let’s say, which is, again, transplantable.”

Therefore you have a big concern. The theological question is, does this body belong to me? Is it mine to make a decision, for me to go ahead and donate parts of it or should I be the one deferring to religious authorities telling me what to do? Because I as an ordinary Muslim I don't think the body belongs to me. My body belongs to God. And certainly I am not in a position, for example the law says, Islamic law says quite clearly, that you cannot make a *wasiya*, you cannot make a last will of testament, saying that 'I am donating my eyes or I am donating my kidneys,' because that testament is null and void, because the body is not yours, how can you make a decision about it? So there are so many issues in theological circles, and you are right that some of them would rule for it and some of them would go... There is a pluralism of opinions, whether you can donate. But I think that what I find to be the trend in Iran, Iraq, and other places is that—“

EHSAN MASOOD: “In the Shia communities.”

ABDULAZIZ SACHEDINA: “I would say that even from the Sunni communities, Dr. Yasin's work in for example Jordan, a quite famous bioethicist, he is a Sunni bioethicist, Shafi'i school (one particular school of Sunni thought) you will find that they are supporting organ donation, although they are not convinced that you can charge anything. The monetary advantage is ruled out. But out of altruism you can do it, because ultimately it is going to save somebody's life.”

EHSAN MASOOD: “For those in the Shia tradition who do not agree, what is their reasoning, what is their justification?”

ABDULAZIZ SACHEDINA: “They would simply say that it is beyond our jurisdiction to make any decision about our bodies. We need to leave it to God. And 'I would rather see myself be buried after my death than someone retrieving organs from me.' There is also this belief in the soul, that you mention, what happens to me on the day of judgement.

“I was consulted, for example, in the Mercy Hospital, when the Iranian boy, 18-, 19-years old was injured very badly, and the hospital wanted to retrieve the organs, the corneas especially. And the Iranian mother could not come to terms with 'what will happen to my son on the day of judgement. Will he be awakened without his eyes.' You can see the emotions and the connections that human beings have towards each other's bodies. The mother, she loves the son. It was a very pitiful situation, and it was hard to convince her. I used the Qur'an saying that God did not need all these bodies to bring you back in life. You were nothing, he brought you to life. Why won't he be able to

bring your son's eyes on that day of judgement. She was not convinced. Emotionally, she was drained. She could not agree to it.”

ROBERT TAPPAN: “The theological perspective can certainly account for this: God created you from nothing in the beginning, he can do it again.”

EHSAN MASOOD: “Asim, let's move to you. We talked a lot about the father, and the range of perspectives that come from within the Shia tradition. Let's move to the majority Sunni tradition. This is the situation that the mother will be facing. What are the spectrum of views which a mother in this situation is likely to encounter.”

ASIM PADELA: “In my reading of the Sunni tradition, there are three dominant opinions. They each have their own basis within the Qur'an and the Sunna. The first opinion is that no donation is permissible. And that is on the basis of a theological argument with a legal argument as well. The theological argument runs that if the body has *karāmah*, is endowed by dignity by God, has *ḥurmah*, has inviolability, beyond the fact that it is the vessel for the human being, it itself has inviolability even when it is not the vessel for the soul. This comes from a hadith—“

EHSAN MASOOD: “A hadith is a tradition or saying of the Prophet Mohammad.”

ASIM PADELA: “Exactly. There are many traditions. One of them is about the fact that breaking the bone is like breaking the bone of the living person. And this is in the context of a grave digger; there are many different contextual issues.”

EHSAN MASOOD: “And this is an authentic tradition that is agreed upon.”

ASIM PADELA: “And there are multiple versions of it. And in any case, from that, they said, look, even the dead body has some dignity and it is inviolable. So the point being that it is a theological argument, one, that based on *karāmah* and *ḥurmah*.”

EHSAN MASOOD: What do those two words mean?

ASIM PADELA: “So, *ḥurmah* is inviolability, *karāmah* would be dignity. And on top of that if you think that the human is a bunch of body parts, you lead to a further theological reduction of the dignity of the human being as a special creation, and that's what happens with the organ markets.”

EHSAN MASOOD: “So that’s one of the three.”

ASIM PADELA: “That’s one of the three. The first. So it’s not permissible, it’s *haram*.”

EHSAN MASOOD: “And *haram* means—“

ABDULAZIZ SACHEDIAN: “Forbidden.”

ASIM PADELA: “The second stream of thought is that it is contingently permissible. So the contingency is that there is a dire need, *darūrah*, or a life threat. And this comes into play looking at the society at hand. We often talk about organ donation and organ transplantation as a cure, as a societal need. And we should know that there are, for example, kidney donations—there are other remedies science has. You have dialysis. In your own home country, in the UK, after a certain age they do not pay for transplantation, because they think you have the same life expectancy with dialysis that you would with an organ. So this idea that we have multiple cures. But most often the scholars will say, no, this is a cure for a dire need. The person will die. So this is the language. We said life-saving. Not every organ is life-saving. A kidney could not be life-saving.”

EHSAN MASOOD: “So just on that perspective, could you give us the theological justification for that second perspective?”

ASIM PADELA: “The life threat. What I’m trying to give you the sense of, when you say “contingent based on life threat;” we have to understand if there is a life threat, if there will be a life-saving organ. Not every organ is life-saving. A cornea is not. A kidney might not be at a certain stage of life. So that contingency is that there is a life-saving aspect to this organ transplantation and there is no other therapy. So that is the second.”

EHSAN MASOOD: “And the third.”

ASIM PADELA: “The third stream says that it is based on public benefit, *maṣlaḥah ‘āmmah*. Now it is permissible... Let me give you a fourth thing here, because of language. We talked about deceased donation and living donation. Now you talk about brain death; brain death is not considered deceased donation. At that stage, if you don’t believe brain death is death, as Professor Sachedina said. We need to understand that each one of these opinions ride on a conception of

death which may or may not accept brain death as deceased. And if it does not, then you can't use that argument for donation."

EHSAN MASOOD: "Which is the point that, Professor Sachedina, you were making earlier."

ABDULAZIZ SACHEDINA: "Right, right."

EHSAN MASOOD: "Let's move on, in the sense, that if this was Europe, or if this was the UK, there is a post-holder in the public health care system called the chaplain. And all hospitals that are in the public system, more than nine out of ten, would have a Muslim chaplain. And the Muslim chaplain would be an employee of the national healthcare system. And he or she would work very closely with the different clinical and non-clinical staff in these kinds of situations. Now, more often than not, the Muslim chaplain would enter into these conversations and, the interesting situation that has emerged is that obviously because of a shortage of organs, and there is a world-wide shortage of many types of organs, there is a particular shortage amongst Muslim families."

HASAN SHANAWANI: "A lot of the discussion that we have had so far is about the tragedy of Sara, of course, and the loss of life for this particular individual. It might be worthwhile for me, we've talked about *maṣlaḥah* and the public benefit, let's talk a little bit about that for a moment. For every organ that gets donated, depending on the organ that gets donated, be it heart or lungs, we have between 10 and 15 people that are waiting on the transplant list. So, there are long lines of people whose lives will be potentially prolonged. So there is a substantial public health need, I would argue, that is benefitted. And the limiting factor, for the most part, is the supply side. That is to say, that we don't have enough willing donors. You mentioned at the beginning in your introduction, of the person whose organ didn't last very long after it was successfully transplanted. Over the intervening 65 to 70 years the science of transplantation has really been substantial, the technology, the medications that allow organs to last longer. Most kidneys last between 15 and 20 years, now. Lungs last between 10 and 15 years. So people's lives are substantially improved and lengthened. So for me as the clinical provider who is working for the organ donation, with all respect to the discussion that we've been talking about, I'm looking at these 10, 11, people, really 50 or 60 people if you think about each organ and the 10 people who are waiting for one of those organs, I'm looking at all of those people. And so it may seem morbid to reduce this issue to some simple actuarial, but the reality is that that's really what this comes down to, doesn't it. It is not my job to advocate for Sara. I have my own Sara who is going to die unless she gets a new heart. And her family, they have concerns too. And I would argue that that person has her own dignity. Now,

every goal has a method, which becomes a task. And one would argue that if my goal to preserve the dignity of my own Sara which is about to die because her heart is about to fail should not infringe on the right of this other child who has died. But that's not my concern, as the transplant physician."

EHSAN MASOOD: "So, Najah, let's go back to you now. You've heard, in a sense, a perspective you may well have heard many many times from a representative such as Hasan. How would the family respond?"

NAJAH BAZZY: "There are families who reflect back that they feel an injustice. And what makes them want to donate the organ, or the organs, is that they feel that, to your point, if their daughter needed an organ, they would be in the shoes of the family that is waiting, and they would do anything to save the life of their daughter, because God has commanded us to do everything we can to save life. I have found more than a handful of families who have struggled with the idea that Islam, depending on their school of thought, may forbid them from doing something that they actually want to do. But they don't feel that they have permission. They have permission to receive, and the benevolence of receiving, but not give. That is a very interesting dynamic. I have families who have shared with me that their scholars and leaders have discussed with them that Muslim organs have a certain sanctity to them. For example, the heart, has this idea, spiritual *muwahhidin*, that they believe in the one-ness of God. And that their heart has never enjoined any partner to God. And, please help me through this. And that a liver, for example, has never been intoxicated with alcohol, which is forbidden. Or the body has been sanctified in the sense that it has never had pork products. And so, there is this discussion about, it's OK to receive organs, who may not have been and then once they're in the Muslim body, they are somehow purified, but to give the purified organ to someone who may, what's the correct word, I'm trying to be—"

ROBERT TAPPAN: "Shepherd?"

NAJAH BAZZY: "Who may intoxicate it in some sort of sense, or de-sanctify it, I guess is a better word, that becomes psychologically troubling."

EHSAN MASOOD: "Najah, as you mentioned, the clock is ticking. There often isn't a huge amount of time to make decisions, and these are laden with complex theological issues, with unimaginable emotional burdens. And then of course the weight of expectation of society and community and family. But the clock is ticking, and a burial has to be performed, so one by one, starting with you,

Asim, what would you say to the family, if you were called to advise in a sort of chaplaincy role for example, what would you advise.”

ASIM PADELA: “And I think we skirted the chaplaincy question. But the question is, what is the role of the chaplain. We have model standing for the physician. And a good barometer for this is Emanuel’s and Emanuel’s four models of the patient-doctor relationship. Ezekiel Emanuel and Emanuel, both of them whom I knew. And they talk about four models, one of them is, you are an informant, you just tell the family what to do, and they decide. One model is that you are actually a deliberative agent. You and the family together put out the moral values-laden questions and together make the decision. There are two moral agents here, in the physician’s case, but also in the chaplain’s case; he is advising a family. So you come together in the deliberative model. There’s a model... And in that sense you are a moral guide. There is an interpretive model where you just take the family’s values, you interpret them into the medical scenario, and you give back what they want to do. And there is the paternalistic model where you override. And they say that the deliberative model is the best, there are two moral agents. So if the chaplain is an agent, they are not agents of the state, they are autonomous agents as well in a moral action, they can claim conscience if they do not want to participate in something. If they are following the deliberative model, they tell the family, ‘here is what I think.’ And I was involved in a case in the UK, there was a big case where he did not promote organ donation—“

EHSAN MASOOD: “The chaplain did not promote—“

ASIM PADELA: “Because he felt that it was impermissible according to the law that he followed, the Hanafi law, and they were saying, ‘well, you’re a state actor.’ ‘No, I’m a moral agent in a conversation.’ If I were that person I would have a similar view. I, contrary to Hasan, believe brain death is a dying state. That is the Islamic position that I hold. It is not a dead state. For me, then, only living donation, where you have made your own decree, is permissible. That’s how I think about it. And I would advise the family to do that. But that’s me, my view. I need to understand what their views are. And if they ask me, what are the various opinions, then you give them the various opinions, and the reasoning behind it, and say “what guides your heart.” So that is how I would approach the situation.”

EHSAN MASOOD: “So in a sense you would lay out the bounds of what you think is—“

ASIM PADELA: “Here are the guidelines of various agencies and fatwas that come out. Here is the basis, here as a physician and an Islamic bioethicist I can critique each one of those and tell you what the basis is; what do you want to follow.”

EHSAN MASOOD: “Robert, the clock is ticking, what would you advise.”

ROBERT TAPPAN: “Yeah, and I think maybe this discussion shows that even a well-trained chaplain isn’t enough, and perhaps we need to think in terms of... Perhaps for a non-Muslim patient facing the same situation we might have an entire hospital ethics committee who would talk about these things in different ways. In some Muslim countries they have those, at least on an ad-hoc basis. Maybe you need multiple people from multiple perspectives at least that relate to your patient. In this case we have two parents from different schools of thought, so maybe the need is even greater, to walk them through these options. Also, I think there is something really important about not assuming this is simply a *fatwa* argument or something like that, but what is the dynamic between the parents. If I’m the Shia father, and I make one decision, how is that going to affect my Sunni wife. Is it something she agrees with, is it something she is going to resent? Parents already have those conflicts, let alone bringing in the religious element.”

EHSAN MASOOD: “Aziz.”

ABDULAZIZ SACHEDINA: “I think it’s very important for our listeners to understand that whatever I say or anybody says, I don’t think I am in a position to advocate my own stance on an issue, but I would say that I am a chaplain in the hospital, I work as a chaplain, and I also see patients from different traditions, so I am not simply limited to Muslim patients. We are the ones who are negotiating it with their families. We simply recommend what we tell them. We are not in a position to decide on their behalf.”

EHSAN MASOOD: “Would you... It’s clear from both Asim and Robert that they would in fact not so much make a recommendation as to lay out what a position is and what the evidence might be, and then, in a sense, close the door at that point. Would you agree with that or would you actually go one step further and say, ‘you know, I think you should do X.’”

ABDULAZIZ SACHEDINA: “There was the case of the Iraqi man who had a stroke, this was the third time, and the doctors told me, they called me at nine o’clock in the evening, I went to the hospital, they said, ‘we cannot revive this person. Anything we do is futile. He is not going to

survive.’ The wife was the one who was working, and they had to make a decision about discontinuing life support. And they were torn because they were Iraqis, they were the followers of Ayatolla Sistani, who said, ‘once you start the machines, you cannot stop them.’ But Ayatolla Sistani, sitting in Najaf has no idea that a woman who is working and supporting this man, and now she is in a position whereby she is being asked to say, ‘ok, ventilator is OK for years, I will now take care of her, him, and the hospital’ and the insurance company is not willing to pay either. So here you have a very complex situation. What can Islamic Sharia say to such a situation. Is she supposed to give in to what the doctors, the specialists, are saying? I have dealt with those cases and I came out saying that the only thing you can do is recommend for you that this is the right course of action; it is up to you to make a decision about it.”

EHSAN MASOOD: “Asim, you wanted to briefly come in.”

ASIM PADELA: “So I want you to understand that as a chaplain in the United States, the model is non-directional counseling. Which means, just, doing an informative model. There are models in the Muslim world where that is not the modus operandi. For example, in Saudi Arabia, they are called ----, and you are supposed to actually help a family make the right decision religiously, theologically.”

EHSAN MASOOD: Do you have an example of that?

ASIM PADELA: This case, in Saudi Arabia, if this case was happening, Saudi Arabian law has organ donation, they permit brain death, and they would, if the family is struggling with how to reconcile their faith and the theological argument, they would present them theological arguments. So my point only is that we have to understand the context. And here in CP [clinical practice] it is non-directional. That is not the case everywhere.”

EHSAN MASOOD: “I want to come to you, Najah, as the family representative, having heard what you have, and obviously having been in these scenarios, unfortunately, many many times. What would you say?”

NAJAH BAZZY: “My role is to first try to understand what the patient’s will was, and to assess that. And then to help the family. Now, I am not in a position, nor will I ever put myself in a position, to rule. It’s not my job. I can only rule for myself. So my goal is to facilitate the discussion, make sure the questions have been answered appropriately. Get people what they need, and allow safe space

so that when the person is buried, the family is left intact, and the person who has passed on is left intact. What determines ‘intact’ is not up to me. It’s up to the family. So I am the facilitator of conversation and the gatherer of knowledge, or the person who is helping people connect the dots, whether it is from Gift of Life or their scholars or their community or just themselves. And this isn’t just for Muslims that I do, I do this clear across all of my work.

“We burden families as well, making medical decisions that they don’t have the knowledge to make. And so I often speak about this idea of how sometimes absolving a family—“

EHSAN MASOOD: What do you mean by “absolving”?

NAJAH BAZZY: “Meaning that you need to leave the family in a position where they can grieve without guilt. I have spoken to Hasan Shanawani about this, that sometimes when the family really cannot make this decision, and they feel burdened to the point where they can’t even grieve the loss of their loved one, then there is something wrong with the way that we are doing medicine as well. Vice versa, though, if a patient believes in something, regardless of their religion, I would advocate for that patient’s right to leave this world the way they believe they needed to.”

ASIM PADELA: “The work that has been done on Muslim attitudes towards organ donation in diasporic communities: UK, Australia, United States, right, including my own, I’ve done two large studies, shows that Muslims have more negative attitudes towards organ donation than other populations across the board. And about 40 to 50% of that negative attitude is lack of religious knowledge about the permissibility, impermissibility, and whether those things apply contextually to their loved one. So there is a huge knowledge gap in the lay Muslim community about what the religion says, and whether it applies now. As far as Muslim physicians, in my national survey of Muslim physicians in the United States, 79% felt more troubled by withdrawing life support than withholding it. 46% did not agree that brain death was equivalent to cardiac death, so the Muslim physician community, that is, more than 5% of doctors in the United States, is particularly troubled with end of life care scenarios. And this has a religious inflection, but also a practical inflection upon what they do every day.”

EHSAN MASOOD: “Robert:”

ROBERT TAPPAN: “I’ll try inefficiently to channel my colleague Sherine Hamdy who wrote a great book about organ donation and think about the context in which these cases happen, and just to

think about what she saw in Egypt. Again, religion doesn't always map over to decisions. So she provided examples of physicians who are part of the Muslim Brotherhood who said 'brain death is fine' and said 'cadaverous transplantations are fine' and vice versa. So there are other factors that are going on in any particular place and case that could influence why, 'I may not simply follow this scholar Sistani or Fadlallah out of tradition, I might have a certain feeling that in this particular case my loved one's organs are being taken away unjustly, or I am not part of a fair system, and that might be the reason why I am not interested in donation. Whereas in a more just distribution, not perfect, but a more just system like the United States, maybe I've seen that system work better and I'm more open to a justification, a religious justification, that corresponds to that.'"

ABDULAZIZ SACHEDINA: "I think that my take on organ donation, or working towards encouraging Muslims to donate organs so that they can help other patients, I must be, I must state very humbly that I don't think there is any absolute position, that I need to indoctrinate my patients, whom I go and see, or even the community. Rather, my suggestion has been to think altruistically of how they can help others. Because I think modern medicine has impinged upon the natural course of life and we have somehow submitted, unquestioningly, to the medical advances without thinking what kind of issues are they creating for the families, for the loved ones who are left behind, after all, death is not only for the person who dies. Death is for the ones who are left behind."

EHSAN MASOOD: "We have come to the end of our exploration of this complex and very difficult subject. I would like to thank our panelists, Asim Padela, Robert Tappan, Abdulaziz Sachedina, and playing the role of family representative, Najah Bazy, and in the role of health care systems representative, Hasan Shanawani. Thanks also to the Contending Modernities program, at the University of Notre Dame. Thank you.

"There are at least two possible endings to this story, probably more. But rather than lay down an ending, I want to leave the final decision on the best outcome to you. If you were Sara's family, what would you do?"