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The Ethical Framework for Surrogate Decision Making

The physicians need to rethink how we reach decisions with surrogates. You are listening to ReachMD XM 160, The Channel for Medical Professionals. Welcome to the Clinician's Roundtable. I am your host, Dr. Maurice Pickard and joining me is Dr. Alexia Torke. Dr. Torke is the Assistant Professor of Medicine at Indiana University Research Scientist at the Indiana Center of Aging and also the Director of the Ethics Fellowship at the Fairbanks Center for Medical Ethics.

DR. MAURICE PICKARD:

Thank you very much for joining us.

DR. ALEXIA TORKE:

Thanks for having me.

DR. MAURICE PICKARD:

Recently you had a paper in the journal on clinical ethics which focussed on this whole tension that may exists between doctors and surrogates, but before we get to that, could you tell me as a background how have we dealt with surrogates and what is the standard bioethical approach to surrogate decision making?

DR. ALEXIA TORKE:

Well, the basic issue is that a lot of adults at some point during their medical care lose the ability to make their own medical decisions and ethicist have tried to come up with a standard framework to help physicians and family members when they are making decisions for these patients and the standard approach has generally involved 3 standards. The first one is advanced directives where we ask individuals to indicate the kind of care they would want to have if they ever became unable to make decisions in the future, so this is something that we ask people to do before they lose their capacity and then we can rely on these documents for decision making. Unfortunately, most people do not have these documents and so we often have to turn to the second standard which is called the substituted judgment and in this standard the surrogate attempts to make the decision that the patient would have made and this can be based either on statements that the patient has made or even under general beliefs and values. In some cases, we do not really know what the patient's would have wanted at all and then turned to the third standard of best interest in which decision makers try to determine what is best for the patient overall, usually using their own judgment and their own values.

DR. MAURICE PICKARD:

Well, this is what we all learned in medical school, but has not there been a lot of criticism about how this actually plays out at the bedside?

DR. ALEXIA TORKE:

Yeah, there has been and there are really at least 3 main arguments for why the approach is problematic. The first is that when people have done studies in which they ask surrogates and patients to indicate the kinds of therapies they would want. In certain situations, they found that surrogates are actually pretty inaccurate. The way they generally do these studies is that they will take a patient into a room and ask him a question about the kind of care they would want if they had a particular medical condition and then they take the patient's presumed surrogate decision maker into another room and ask him what they would do for the patient in that circumstance and they found that there is a lot of disagreement. In fact, overall physicians and surrogates probably only agree about 68% of the time and so the first problem is that surrogates are just really not very good at predicting what the patient's would have wanted. A couple other concerns – one is that patients even change their own mind over time. There have been several studies that have asked the patients at time when they indicate the kind of treatment they would want for a particular medical condition and have been gone back enough from later and they found that a lot of people really do change their minds and it makes sense given that their health conditions change. The third problem is that the patients actually want their families and physicians to have a leeway in decision making if the patient were ever to lose the ability to participate. So, patients really want their surrogates to have some choice in the matter. So, those are 3 things that really kind of pose a challenge to the idea that we should rely on patient's wishes as our first standard for surrogate decision making.

DR. MAURICE PICKARD:

Do doctors themselves have a problem with this. I know this is your research. How did doctors go about responding that this does not really working out the way I thought it would?

DR. ALEXIA TORKE:

You know what we found in our research is that we did ask physicians to articulate what they thought was the standard ethical approach and by and large they described that 3-step process, but then when we separately asked them to describe what they have done for a recent patient, there was much more variety in their approach. So, I am not sure that the physician would necessarily be able to say I know this is the right approach, but I was not able to follow it for 1 reason or another, but what we find is that even though they are aware of the standard textbook approach, when it comes to making a decision for a real patient, their approach is much more complex.

DR. MAURICE PICKARD:

When you interview these doctors, were there any particular scenes that arose that you could focus on and deal with?

DR. ALEXIA TORKE:

When we ask them to describe the most recent patient for whom they made as a surrogate decision, we found that they did use standard ethical approach as to some extent, so there were for example physicians who really said, "I tried to do what the patient would

have wanted or indicated that they encouraged the family to do what the patient would have wanted and other times, they explicitly used the phrase of “best interest.” I really tried to do what was in the patient’s best interest, so I tried to seal the family towards what was in the patient’s best interest. One thing we found though is that some patients relied primarily on patient’s wishes and some relied primarily on best interest and sometimes they did not seem to have insight into what they chose one or other. In addition to those major categories, we found that physicians also consider the surrogates wishes and interests which really does not appear anywhere in the traditional framework. So, for example, sometimes the physician would ask the family member what do you think we should do here and they would just take the family member’s statement as face value without really exploring whether it was based on any kind of patient’s centered principle such as patients wishes.

DR. MAURICE PICKARD:

And then there was a third, I think, where the physicians himself begin to rely in his clinical judgment and what he personally felt was right for the patient.

DR. ALEXIA TORKE:

Yeah, we did find that to be the case. A lot of times in the traditional frameworks and even in some state laws the surrogate is supposed to be the one who speaks for the patient and so the surrogate meaning the family member or significant other is posed to articulate both what would be best for the patient and also what the patient’s wishes were, but we found that physicians also thought that they are to play a role in determining what was best for the patient and they justified this based on a couple of things. One was their clinical expertise, so they really thought that because of their clinical background that they were able to best understand what was going to happen to the patient, what was a likely outcome, and that they should bring that input into the decision making and the second thing is that physicians really felt a duty to determine what was best for the patient and in some cases even to try to convince the surrogate of what they thought was best.

DR. MAURICE PICKARD:

We are talking about the tension that may develop between physicians and surrogates and certainly I personally have always found this to be one of the most difficult situations in medicine. It is so much easier to deal with a competent patient and to direct them or at least give them your advice. Now, you are dealing with a person that possibly has never seen you before. You know I know that your article you talked about clinical judgment and the physician always wanted to do what was right for the patient. I wonder though there were several different kinds of physicians in your paper and if we just focussed on interns as opposed to attending them, did you notice any difference in how they dealt with it, some of these interns, this might be the first patient they ever had to deal with as far as a surrogate that were part of your research. Others might have been an attending man who had gone through this many, many times. Did you see any difference there?

DR. ALEXIA TORKE:

You know unfortunately, because this was a very small study really involving 20 people, we were not able to sort out those differences. We did find that when interns were involved in decision making, they often sought advice from the residents or attendings and a couple of the attendings that we interviewed described giving advice to their teams about how to do surrogate decision making well. So, we did find that there was a discussion among the team, but in future research we do want to look a little bit whether there are differences between the experience of those physicians who are more junior and those who are more senior as far as the approach to decision making.

DR. MAURICE PICKARD:

The other thing that struck me when I arranged you paper was and this has to do with really my personal contact with my colleagues. How often physicians do not deal with their own mortality on a personal level that many of them do not have a living will, many of them do not know who their surrogate would be, may of them have never been surrogates. I wonder how their own personal experience motivates them to their contact with other surrogates.

DR. ALEXIA TORKE:

Yeah, I think it will be interesting to explore that. We did not specifically explore that in the study, but it certainly is the case that many physicians do not have a Living Wills or other advanced directive documents and they certainly mere the general population that a lot of people do not feel these documents out and do not have them available when they became seriously ill, but I think that would be a great question for future research as the extent to which physicians own experiences with their willingness or lack of willingness to deal with their own mortality might affect their interactions with family members.

DR. MAURICE PICKARD:

I am sad on many ethics communities as you have and this often comes up and you ask people at the table to raise their hands if they have Living Wills or advanced directives and it is always amazing and of course this mirrors I think the whole medical profession. There is an undercurrent about dealing with their mortality that I think doctors do not want to necessarily deal with and then it expands into how they deal with patients personally. I am sure you know experience this same thing.

DR. MAURICE PICKARD:

I would like to ask you, you know we have no problem dealing with competent patients as far as how do direct them, how to give them information, how to give them choices, what we think is the best thing for them. Why is it different when we deal with the surrogate? Why they were doing this with competent patients, why should we do it with people who are standing supposedly and they chose the patient?

DR. ALEXIA TORKE:

Well, I think you are absolutely right that spending time counseling and supporting the surrogate is an extremely important part of surrogate decision making. I think the reason why we have not paid as much attention to that has at least 2 reasons- one is that we have tendency to view the surrogate sort of a mouthpiece for the patient or as an objective individual who is going to help us make decisions for the patient who can speak for themselves. In reality, the surrogate is often a close family member or close friend of the patients and is dealing with an incredibly stressful situation. Often it is a loved one who might be a risk a dying or might be seriously ill and in many cases, the surrogate decision maker is having to cope with all of that while making very difficult decisions. So, I think that conceiving of the surrogate as sort of an objective motionless decision maker is a big mistake. I think the second issue is because we focus so much attention on advanced care planning, we have not focussed enough attention on the process that actually has to occur when the surrogate really has to make a decision together with the physician. So, in my research I am trying to pay more attention to the time when decisions actually have to be made rather than the time when advanced care planning might occur.

DR. MAURICE PICKARD:

The other thing when I read the very scenarios that you described was that very often physicians seem to mix ethics and clinical judgment, they will give a reason which they think is a clinical judgment and it often sounds like an ethical approach and the opposite was also true. Do you find that doctors seem to merge this in a complex way?

DR. ALEXIA TORKE:

Yes, I think that is true. In fact, sometimes I would be surprised when I would ask one of the subjects, a question about why they took a certain action or why they thought a particular type of care was best for the patient and they would give me an answer that was entirely clinical. When I expected an answer, it would be based on ethical principles and it made me realized that in the minds of many physicians those two are very closely lined. I think that probably makes sense in some situations and which for example are judgments of best interest should be based on a patient's clinical condition and/or prognosis and what to expect in the future, but I think it is important that physicians be able to recognize the types of principles or the type of knowledge that were lying on when they make an important decision and be able to identify when they are basing something on an ethical judgment versus on a clinical judgment.

DR. MAURICE PICKARD:

I want to thank Dr. Alexia Torke for being with us today. We have been discussing this very complex issue of reworking and re-looking at ethical frameworks for surrogate decision-making, a problem that's going to become more and more frequent as our population ages.

I am Dr. Maurice Pickard and you have been listening to the Clinician's Roundtable on ReachMD XM 160, The Channel for Medical Professionals. To listen to our on-demand library, visit us at reachmd.com, and if you have comments or suggestions, please call us at (888 MD XM 160). Thank you for listening.

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