

Episode: Ethics Talk: How Do We Know Who's Dead?

Guests: Ariane Lewis, MD

Host: Tim Hoff

Transcript by: Tom Wagner

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TIM HOFF (Host): Welcome to *Ethics Talk*, the *American Medical Association Journal of Ethics* podcast on ethics and health and healthcare. I'm your host, Tim Hoff.

Knowing who's alive and who's dead sounds basic, and our intuitions about death might at first glance be pretty confident. But when pushed, especially in cases that challenge our understanding what it means to be dead, the gaps between our personal philosophical or religious beliefs, legal definitions, and clinical criteria for death become apparent. Media representations of death especially brain death only confuse matters more.

DR ARIANE LEWIS: Some of these issues pertain to the language surrounding brain death determination by which individuals would say, "well this person is brain dead but their body is still alive," or would say something like, "we need to declare them brain dead so that we can donate their organs," indicating that the purpose of brain death determination was for organ donation.

HOFF: Caring for patients at the end of life and helping families and surrogates navigate the uncertainties around death is a key part of clinical practice. Diagnosing death requires not only an understanding of its clinical criteria, but also a keen grasp of how our relationship to death is both culturally and socially situated.

With us this month to help work through this topic is **Dr Ariane Lewis**. Dr Lewis is a neurointensivist in the Division of Neurocritical Care in the Department of Neurology at NYU Langone Health in New York City. Along with Dr Thaddeus Pope, Dr Lewis guest edited the December issue of the *Journal*.

Dr Lewis, thank you so much for joining me.

LEWIS: Thanks for having me.

HOFF: Diagnosing a patient as dead involves practicing at the intersections of among clinical criteria and legal standards, and social and cultural conceptions of what it means to be dead. And each of these categories themselves then contain sources of ambiguity and involves organization-based and clinician-based variations in practice. This is obviously an incredibly broad topic, so we'll start with a nice easy question. When is a person dead clinically?

LEWIS: So you might actually say that's a nice easy question but actually it is a little bit complex as well [laughs]. I will say that in terms of the criteria for brain death determination from a medical perspective, in the United States we have two sets of guidelines for adult and pediatric brain death determination. The adult guidelines were published by the American

Academy of Neurology initially in 1995 and then updated in 2010. And the pediatric guidelines were initially published in 1987 and then subsequently updated in 2011 by the **Society of Critical Care Medicine**, the **American Academy of Pediatrics**, and the **Child Neurology Society**. These two sets of guidelines which are the most current accepted medical standards for brain death determination are very similar, but there are subtle variations between them, and these variations hinge upon the fact that different sets of authors wrote them and not that there's a different physiology between the two populations but rather they were written by two different groups. As a result, actually at present a new set of guidelines is being put together that's going to be for both the adult and pediatric population which we hope will come out within the next year or two.

HOFF: Great, thank you. So this need for consistency between approaches to brain death is apparent. So why is there so much confusion among individual clinicians and also amongst most of the public about when somebody is dead? Why is there this variation in how these clinical criteria are either being interrupted or applied?

LEWIS: So, the basic tenets behind brain death determination are first that this is, that the person has suffered irreversible, catastrophic injury to the brain and so it's necessary to identify what the etiology for this injury is. It's also necessary to ensure that a person has met prerequisites for brain death determination mainly that there's no other factors that could make it seem as though the person is brain dead when they're in fact not. Those are things like making sure they have an adequate blood pressure and appropriate temperature for brain death determination, making sure that there aren't drugs that could potentially interfere with the evaluation or any other clinical factors that could make it seem that though the person is dead when they're not. And then the exam itself requires an evaluation to determine that the patient is comatose and has brainstem areflexia and is unable to breathe spontaneously. In some cases, it's necessary to conduct ancillary testing to determine whether or not there's any electrical activity in the brain or whether there's any blood flow to the brain.

In terms of how to go about doing that, there's certainly can be some confusion because there are nuances associated with the brain death determination process. As a result, it's very important to ensure that there's are no mistakes and no false positive brain death determination. So on the part of clinicians that could lead to some confusion about the intricacies of the determination process. In this issue, Diana Barratt addresses the means to prevent false positive declarations and Dave Greer also addresses issues pertaining to institutional inconsistency.

In terms of the public perspectives on brain death, the public in general hasn't heard of brain death or if they have, then they think it's the same thing as a vegetative state or a coma. And this is largely based on the fact that brain death determination is not something that's discussed commonly, and when it is discussed in the media or in TV or in movies, misrepresentation is present and it seems as though brain death is not an actual state of death that is equivalent to cardiopulmonary death. And in this issue Katharina Busl also addresses the issues pertaining to public perceptions in brain death determination.

HOFF: I wanted to ask a little more about what kinds of misrepresentations of brain death you see most often that might confuse people. You say as an example that it's often not represented

as equal to cardiopulmonary death. Are there other things that are commonly misrepresented about brain death that you think are important for the public to know?

LEWIS: Absolutely. So, in a review of TV shows and movies that included a character who is declared brain dead there are lots of inconsistencies associated with the process and the portrayal of brain death determination that deal with a wide array of different things. Some of these issues pertain to the language surrounding brain death determination by which individuals would say, "well, this person is brain dead, but their body is still alive," or would say something like, "we need to declare them brain dead so that we can donate their organs," indicating that the purpose of brain death determination was for organ donation, which is never the purpose of brain death determination. Brain death determination is to make a distinction between life and death, and subsequently, patients who are brain dead have the potential to be organ donors, but that's never the impetus behind brain death determination.

Other issues that have been found in TV and in the movies are associated with the process of brain death determination. In some cases, they'll just do something like look at the pupils which is one aspect of the assessment for brainstem reflexes, but they'll look at the pupils and say, "oh, the pupils are nonreactive this patient is brain dead," which is just a tiny portion of the brain death assessment. So, what is shown in TV and movies is really just a very small bit of what is a very nuance and complicated assessment. And, so it over simplifies it and in many cases actually can make it seem as though there are different incentives for clinicians to declare a patient brain dead, such as organ donation or some financial incentives or some other indication from a social perspective as to why one would declare a brain death. And that's completely separate from the medical process of brain death determination which can be quite confusing, obviously, it puts a negative air on that.

And then in terms of the media, their coverage even of stories pertaining to brain death determination can often be misleading and use phrases like, "the patient is brain dead but they're still on life support," or, "the patient is brain dead and the family has to decide whether they want to take them off life support," or things that are misrepresentations of the actual sequence of events associated with how brain death is declared, and what happens after brain death is declared.

HOFF: Interesting, thank you. You recently participated in the World Brain Death Project, and in August you were part of a group that published recommendations for brain death determination, and since this will very likely be a landmark publication in brain death literature, given its success so far, can you please give us a brief overview of the project, and why the work that you are doing has been so important?

LEWIS: Absolutely. I spoke previously about what the guidelines are for brain death determination in the United States, but I didn't note as of yet that there are different guidelines in different parts of the world, and so studies have demonstrated that there is variability in brain death determination guidance from country to country and in some cases even within countries internationally from institution to institution. And obviously this is quite problematic because it lends itself to the potential for a person to be declared dead in one place but alive somewhere else. While there are similarities and gross similarities between these guidelines there's also

some subtle differences, and these subtle differences can be quite profound when you're looking at the difference between whether somebody is determined to be alive or dead. There isn't really any room for error or variability from place to place with respect to the distinction between life and death.

So the purpose of the World Brain Death Project was to convene internationally experts in brain death determination and allow them to come to consensus with regards to a number of aspects of information pertaining to brain death determination including the minimum clinical criteria for brain death determination, steps pertaining to ancillary testing, and when ancillary testing is need, information pertaining to education and training about brain death determination, and documentation about brain death determination, legal aspects of brain death determination, religious considerations pertaining to brain death determination, situations in which organ support should be continued after a brain death determination, and the ideal means to do so. There's a lot of different topics that are covered within the World Brain Death Project. This was published initially online in August in *JAMA*, and then was published in paper form in September in *JAMA*. There's a lengthy article that summarizes the recommendations put together by the international experts that were part of the World Brain Death Project. Then there are multiple supplements online, there's 15 different supplements that address these different subtopics on brain death determination. And the guidance that's provided in these documents as I said was written by international experts, but additionally has been endorsed by five world federations and also by multiple international societies that have involvement in the process of brain death determination. So this is definitely something that has received international approval pertaining to these guidelines. This is not meant to replace any individual country's brain death guidelines, but rather, this is meant to serve as guidance for each country or medical organization that has their own criteria pertaining to brain death to allow them to review this international consensus statement to be able to come on to the same page so that from one place to another the process of brain death determination is similar. Recognizing that there is the potential need for variability with respect to local resources or access to materials that would be different or religious or social considerations or legal considerations from country to country. But that the goal is for the minimum criteria to be met across the world.

HOFF: One of the limitations that's noted in the project is the lack of wide-scale randomized clinical trials on brain death and death determination by neurologic criteria. Why is that an issue? Why is there not enough evidence and why has it been hard to collect evidence at a large scale that can be used to help establish these global practice standards?

LEWIS: I think it's important to recognize that the process of brain death determination and the exact state of brain death is not something that was a discovery. This isn't like, you know, one can review particular data pertaining to this and then make an understanding as to what is the distinction between life and death. Brain death, and death in general, is involved... this is a social construct and this is at the basis between and the border between religious views, philosophical views, scientific views, medical views and so there a lot of different perspectives on what death is. But here, you know, what the purpose of this document is to come consensus as to what are the medical criteria for brain death determination. But there's no data that one can find that could support what is death or what is not death. Rather this is more of a belief system as to what are

the criteria that reach a certain point and what is that point that we define as the distinction between life and death.

HOFF: So, our issue this month focuses especially on this question of the social situatedness of brain death determinations. In your letter from the editor introducing this month's issue you write that "brain death is not a scientific discovery, but rather a socially situated diagnosis." Now this might sound unintuitive or surprising to people who think that, essentially, when you're dead you're dead. But brain death can be clinically and ethically complex. So how should social and cultural considerations from either religion or law be part of this conversation?

LEWIS: As I said, I think it's really important to recognize that there are a lot of different perspectives as to when death occurs similar to the varying perspective as to when life begins. There's been long-standing arguments as to when the origin of life occurs - whether it's at the moment of conception, whether it's at the moment of delivery, whether it's somewhere in between - and I think that this same set of arguments have been mirrored at the end of life as well in terms of what is the moment in which we define a distinction as having occurred in the state between life and spanning into death. There are many different views that impact that from religious and philosophical and social consideration.

But I think that it's very important to recognize that there does need to be a finite line. And so while everyone can have their own individual views, this is not an area in which everybody can have their own individual views and there's no interdependence. There's a need for us to have within society a finite threshold as to when there is a distinction between a person being alive and being dead for a number of different indications due to legal considerations, medical considerations, and social considerations such as the initiation of mourning and other events that occur following death. In this issue, we explore the different social, religious, and legal implications associated with brain death determination and the ethical aspects that one should consider in thinking about brain death determination. As a result, we have a wide array of different authors who contributed to the issue with many different backgrounds.

HOFF: Sure. So one of the consequences of this indeterminacy of the line, sort of speak, is that clinicians might find themselves in a position of having to have a conversation with either patient's family or surrogates who aren't familiar with or don't accept the clinical criteria for brain death. So how should clinicians begin that conversation to bridge that gap between their own clinical understandings of brain death and a patient's family member's ideas about death? How can you draw on expertise from colleagues to help people work through this confusion?

LEWIS: I think it's necessary to recognize that, as I said, families often have misconceptions as to what brain death is or they don't have any understanding as to what brain death is when they first approach this situation. As a result of the fact that there just isn't mass education or awareness pertaining to brain death. This isn't like cancer where somebody says that word and everybody knows exactly what you're talking about and everybody is on the same page. Rather, this is something that there is very variability in terms of perspectives and sometimes there can be misunderstandings, so important to begin the process of talking about brain death determination by facilitating education on this topic. In so doing, it's necessary to be empathic

and to offer an understanding as to establishing good rapport with the family, delivering information candidly and clearly and in a timely fashion that's also culturally sensitive. In having these conversations, if religious objections come up to brain death determination than it is appropriate to incorporate multidisciplinary members of the team including religious officials such as perhaps the individual's own religious officials from their community. Here in this issue two rabbis, Rabbi Weiner and Rabbi Sheer, speak about their perspectives on management of objections to brain death determination. Also Matt Kirschen and Bob Truog speak about these issues as well. This definitely is a very complex situation from a medical, social, legal perspective in terms of how this should be managed going forward. I think that the readers will find this to be very interesting to evaluate the different perspectives on this in this issue.

HOFF: Dr Lewis, thank you so much again for being here.

LEWIS: Thank you.

HOFF: That's our podcast for this month. Thanks to Dr Lewis for joining us. Music as always was by the Blue Dot Sessions. To read the entire issue, "Socially Situated Brain Death," please visit our site, JournalofEthics.org. Follow us on [YouTube](https://www.youtube.com), [Twitter](https://twitter.com) and [Facebook](https://www.facebook.com), [@journalofethics](https://www.facebook.com/journalofethics), for our latest news and updates. And be sure to listen next month when we'll be exploring legacies of the Holocaust in health care. Talk to you then.