

# "Standing at the bedside: so many questions..."

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## Abstract

Standing at the bedside of this 17 year old boy, life becomes a series of rapid-fire questions: who are you?; where did you come from?; what did you want to be?; where did you want to go?; what were your dreams, your desires, your fears?; what am I supposed to do? So many questions...

Yet he offers no answers. Says not a word. Makes not a sound. The machines surrounding us make sounds - that's for sure! The mechanical ventilator, the monitors, the intravenous pumps, the wires, the cables, the lights, the noises! So many noises...

Standing here at the bedside, I can hear the cries, the screams, the pain - emanating from down the hall (his family is torn apart - "understandably so", I say to the boy). They do not want to lose someone so close - so young - not like this, not now, not today. Yet clinically (medically), they have already lost him - he is brain-dead. This patient is no longer a person. This person is no longer an individual. It sounds so straight-forward, so clear, so definitive - yet nobody wants to hear. Nobody wants to accept. Nobody wants to lose. His family will not consent to the removal of these machines. 6 days now - and the noise continues...

"What am I to do?", I ask the boy. "Where am I to go?" "Who should I be listening to?" "How long will this go on?" "How many days or weeks or months should I come here and stand at your bedside?" "What do you want me to do?" So many questions...

And not a single answer. Not from this hospital bed. Sitting down beside him, I continue talking out loud...

- Is it morally acceptable to unplug these machines, right here - right now ?
- Is it morally acceptable to obey your family, and keep everything going ?

- Is it "acceptable" to invade your body with our needles, and wires, and cables, and machines ?

I don't know, my young friend... I just don't know.

I do know that before we (as physicians, nurses, or "healthcare workers") offer a "treatment" (any "treatment") to a patient, we must first understand not only the desired result of that "treatment" but also the manner in which it is to be administered (or removed). We must also ensure that the "treatment" is in accordance with the actual patient's desires - let us not forget, that a patient IS an individual. I also know that we should ask if the "treatment" is BENEFICIAL to THIS actual patient, as a PERSON. And, I know of a patient's inherent right to self-interest... self-determination... self-will.

My young friend, you don't know this - but you were shot in the head six days ago. The bullet went through both sides of your skull and you fell immediately into a state of "unconsciousness". You were brought to the emergency room and I was on-call. From there, we came up here. I had to tell your parents what had happened - a phone call in the middle of the night. And, No - the police have not caught the men who robbed you. Not yet. I also talked to your brother and two sisters in the hallway outside - just beyond those blue doors over there (and don't worry, I caught your younger sister as she started to faint). Every day since has been a struggle - not for you, your vital signs have never wavered - your temperature has never fluctuated - the machines are all doing their job. But for your family, it has been hard... and I understand. You probably don't know what it means to be "brain-dead"...

Well, Kaufman stated that "to establish the diagnosis of brain death, the physician must document the irreversible loss of all brain function while excluding conditions that can

mimic brain death. Confirmation of irreversibility requires continued observation for variable periods, depending on individual circumstances and use of confirmatory tests." 4 days ago, I ordered an "EEG" - it's a brain function test (and don't worry, I didn't know what it meant when I was 17 either). That test revealed no electrical activity in your brain and that night a perfusion study documented a complete lack of cerebral blood flow. You see, Kaufman also wrote that the "absence of cerebral blood flow confirms brain death, since absence of flow results in irreversible damage within minutes". I wish it wasn't true - but, my friend you are brain-dead. And that was 4 days ago.

Both legally, and morally, you are dead. Only those machines over there are creating this illusion. Since you are dead, you are no longer a person. You are no longer an individual. Yet, does this mean that with the loss of life comes loss of self-interests... self-determination... self-will ?

Am I, then, free from the duty to protect you - as a patient, as a person, as a body ?

No - I am not. That answer, I know.

In fact, to truly respect the person as person (the patient as patient), my actions must be based upon that individual's own self-interests. I know that your natural rights (one of them being the right to prevent/avoid bodily injury and/or invasion) do not cease with your loss of autonomy. As Ellman would argue, we each have a "common law right to be free of unwanted physical intrusion". The patient (any patient) must not be subject to a violation of being if we are to inherently respect that patient as person.

Oh, I know ! Some would argue that, in your case, if I unplugged all these machines, I would "unjustifiably infringe upon your family's autonomy". And, I thought about that yesterday after talking with your parents again (we have a conference every afternoon with the head nurse, chaplain, and social worker). I try to answer all of their questions - but, I'm afraid that I must not be doing a very good job... they are the same questions day after day. In fact, I thought your family's "autonomy" a lot last night. On the surface, it seems like a good point - doesn't it ? Their rights, their feelings, their opinions - after all, they did raise you. You are their 17 year old child. But to whom do I owe, as a physician, the protection of rights ? To whom do I owe, as a physician, the act of self-will and self-preservation. If your family's "autonomy" is seen to exist (and I'm not quite sure it actually does), then by what justification is it made equal to

your's ? What rationale can I offer to allow their "autonomy" to intrude upon your self-interest (by violating your being through the act of battery - and make no mistake, since your arrival we have done nothing else but commit battery) ? And, I think Ellman would agree with me; he wrote that "a guardian's or family member's choice is not entitled to the special deference arising from the autonomy principle, for it is a judgment that one person makes about another, not a judgment one person makes about himself". I must admit, my young friend, that at present I can not support the idea of your family's "autonomy". I can not allow their cries to drown out your "voice"; your "being" can not be abused for the sake of other's comfort or "well-being" (not even my own!).

Oh, don't get me wrong. I'm not offering some isolatory action against your family's concerns or sense of loss. I would never suggest that any healthcare-worker abandon, reject, or ignore a family's concerns; we all must take special care to first form an understanding of the situation with everyone involved. As Kaufman suggests, "a number of families may benefit from a short interval to adjust to the impact of a sudden tragedy and to the hopelessness of the situation. This period also gives them an opportunity to develop trust in the physician and in the diagnosis." And I have tried my very best to be supportive - though I'm afraid that one of these days, your younger sister is really going to hurt herself with all that fainting. I agree that a "short interval" of time allows questions to be asked and adjustments to be made. But I must strongly disagree with Kaufman when he writes that "if the family objects to discontinuing the respirator, particularly because of family stress or religious reasons, it may be wisest not to withdraw support." In doing that, I would allow that which I fear most: the loss of patient as an individual by the denial of being through a violation of state! Don't you see... if I keep these machines going, based solely on your family's desire, I place the "well-being" of your family ABOVE my obligations to you as a patient. When you were first brought here and I assumed care, an automatic contract of trust was written. Today, you are still a patient. My patient. You are a body. You are not a person. You are not an individual. You are dead. Even with that, my obligations made at the time of your arrival (obligations inherent in the doctor-patient relationship) must stand.

My friend, sitting here on this bed, I know that you no longer "exist" - not in the everyday sense of the term, "existence" (and with that, another question of "what does it

mean to exist?"). It can not be said that you are "alive" - with any clinical basis. With the loss of life comes the loss of individuality but I can not just morally abandon your right "to be". I must respect your body as a body if we are to respect a patient (any patient) as a person.

I know that.

And I hope that your family will understand. It is time for the machines to stop. It is time for the noise to go away. It is time that I become both medically and morally responsible.

You have taught me much, my young friend – and for that, I thank you. In that same sense, I cannot allow this to continue.

The mechanical ventilator, the monitors, the intravenous pumps, the wires, the cables, the lights - no more.

### **References**

r-0. The reader should review writings of Kaufman, Ellman, Brody, and others that have been so instrumental in this field.

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