Commentary

Debate: What constitutes 'terminality' and how does it relate to a Living Will?

David Crippen*, Mitchell Levy†, Robert Truog‡, Leslie Whetstine§ and John Luce¶

*University of Pittsburgh Medical Center, and Department of Emergency and Critical Care Medicine, St Francis Medical Center, Pittsburgh, Pennsylvania, USA, and †Department of Critical Care, Rhode Island Hospital, Providence, Rhode Island, USA, and ‡Multidisciplinary Intensive Care Unit, Children's Hospital, Farley, Boston, Massachusetts, USA, and §Medical Ethics, Duquesne University, Pittsburgh, Pennsylvania, USA, and ¶Division of Pulmonary and Critical Care Medicine, San Francisco General Hospital, San Francisco, USA

Received: 31 October 2000
Accepted: 2 November 2000
Published: 6 November 2000

Crit Care 2000, **4**:333–338

Abstract

A moribund and debilitated patient arrives in an emergency department and is placed on life support systems. Subsequently it is determined that she has a 'living will' proscribing aggressive measures should her condition be judged 'terminal' by her physicians. But, as our round table of authorities reveal, the concept of 'terminal' means different things to different people. The patient's surrogates are unable to agree on whether she would desire continuation of mechanical ventilation if there was a real chance of improvement or if she would want to have her living will enforced as soon it's terms were revealed. The problem of the potential ambiguity of a living will is explored.

Keywords: ethics, living will, power of attorney, terminality

Introduction

The Case

An 88 year-old woman from a nursing home is admitted by ambulance to the emergency department (ED) with respiratory failure, and an elevated temperature. She has shallow ventilations 50 times a minute and her SaO_2 on a 100% rebreather mask is 80%. Old records are being faxed from the nursing home. The emergency physician intubates the patient and her ventilation parameters improve . Subsequently, a chest X-ray (CXR) shows left lower pneumonia and an elevated white blood cell count (WBC). A large amount of secretions are suctioned out. After some sedation, the patient is resting and ventilating quietly. And her vital signs are stable. The patient carries a convincing diagnosis of dementia. Her family says she was competent when she signed a living will five years previously but has since progressed to the point where she is bedridden, fed by staff, unable to discern place and time but seems to brighten around her family. She has not offered any meaningful verbal dialog for one year. When she is questioned, she offers dysconjugate answers, or looks out the window wistfully.

CXR = chest X-ray; ED = emergency department; WBC = white blood cell count.

In the ED she is sedated for intubation and is non-verbal. She grimaces to painful stimuli, does not open her eyes spontaneously and does not follow simple commands. At this point, the faxed records arrive and the first page is a 'Living Will' declaration, signed and notarized in 1995 by the patient, in which she states the following:

> "I xxxx being of sound mind, willfully and voluntarily make this declaration to be followed if I become incompetent. This declaration reflects my firm and settled commitment to refuse life-sustaining treatment under the circumstances below. I direct my physician to withhold or withdraw life support that serves only to prolong the process of me dying if I should be in a terminal condition or a state of permanent unconsciousness. I direct that treatment be limited to measures to keep me comfortable and relieve pain, including pain that might occur by withholding or withdrawing life sustaining treatment. In addition, if I am in the condition described above, I feel especially strong about the following forms of treatment: I do **not** want cardiac resuscitation, blood or blood products, tube feeding or any other form of hydration or nutrition, intubation and/or mechanical respiration, dialysis, antibiotics, any form of surgery or invasive diagnostic test. In addition, I do **not** want to designate another person as my surrogate to make medical treatment decisions for me if I should become incompetent."

Two blood relatives (daughters) arrive shortly after, and both issue orders

First relative

> "The living will is very clear. I want her extubated immediately and made comfortable with morphine until she dies."

Second relative

> "Wait a minute now. On admission to the ED, she did meet the criteria for the living will and her wishes should have been followed. Following intubation and mechanical ventilation however, my mother is very stable and no longer 'terminally ill'. There is no overriding reason why she cannot be extubated in a day or two and go back to square one. She now has the strong potential to improve (on antibiotic and supportive care) that she did not have before the living will was ignored. Intubation changed all that. Mechanical ventilation is not prolonging death, it is bridging an unstable process so that she may anticipate life. Therefore I say that the living will is no longer relevant. The act of placing my mother on life support supersedes the terms of the living will and we are now in a mode to support her if the odds are such that she has a better chance of life than death."

How do you handle this?

David Crippen

The issue here is that 'terminality' means different things to different people at different times. There is a 'hard' and 'soft' reality to the expression 'terminal'. The hard terminal reality is that this patient is going to die without the 'invasive' treatment she has pre-emptively proscribed because she is in organ-system 'failure'. Organ-system 'dysfunction' such as pneumonia, an elevated temperature and WBC count are different; they are treatable disorders. So if an otherwise healthy patient came to an ED with these symptoms, one would simply treat it. The issue of terminality would never enter into it because the patient is well compensated. However, our patient is different; she has reached the end of her compensatory powers and so we are not dealing with pneumonia, a temperature and WBC elevation. We are dealing with decompensated organ system failure and that is a very different situation.

A gradient sufficiently bad to cause an SaO_2 of 80% on 100% rebreather mask, is 'respiratory failure'. She is unable to oxygenate because of some form of blockage between oxygen carrying structures and the adnexal alveolar capillary. Her pneumonia has clogged a sufficient number of alveoli such that simply increasing the inspired oxygen will not improve arterial oxygenation because it cannot get from the bronchus to the capillary. So the patient is already pushing venous blood (SaO_2 of 80) through her post-alveolar arteriole and there is no way to increase the amount of oxygen available. She is already on the maximum possible without mechanical ventilation (100% rebreather). Increasing the FiO_2 simply increases the concentration of oxygen in the bronchus.

In addition, the patient is unable to ventilate because her functional residual volume has decreased to the point where the energy it takes to move her lungs is greater than her musculoskeletal ability, due to Laplace's law. Therefore, she does not have the energy option to breath deeply; only enough energy to breath rapidly and shallowly, which will not adequately oxygenate her collapsed and obstructed alveoli. A BiPAP mask will not fix this situation. It will not take over the work-to-breathe that mechanical ventilation is designed for. Put the two together and she is definitely 'terminal' because nothing will save her other than invasively inflating her alveoli and taking over the work to breathe. There is no effective 'conservative' treatment. There are only two ways to reverse this self fulfilling prophesy of doom; positive pressure ventilation to splint open the errant alveoli and force them to participate in gas transfer, and mechanical ventilation to take the ultimately fatal work-to-breathe away from the failing patient and put it on an energetic machine.

This 'hard' definition of 'terminal' is a snapshot taken of a finite point on a moving continuum of events. The patient

is interpreting 'terminal' as a unidimensional phenomenon but it is, in the critical care domain, multi-dimensional. Her condition is terminal only if not treated by positive pressure mechanical ventilation, in which case it is imminently curable. For whatever reason she does not desire to take a chance that machines can reverse her organ failure so she would rather die than succumb to them. It doesn't seem to us that she has clearly thought the issue through. That is part of the problem with living wills. It is impossible for me to know if the patient understood all the implications of the living will when he or she signed it or if they still subscribe to a previous interpretation of these implications when they arrive in my ICU months or years later.

Therefore, when such a patient arrives and I read the 'living will' I am in a quandary. They have the autonomy to tell me what they desire done with their body and I am pretty much limited to their wishes no matter how ill-advised they seem. So, if the living will had accompanied this patient, I would have made her comfortable and let nature take its course. So much for dealing with 'terminality' as a blip on a line. However, the continuum of events has moved on and the definition of 'terminality' has moved on with it. As Ms Whetstine says: *"Just because she would have died without treatment doesn't make her terminal, it makes her in need of an intervention."* After she is intubated she is no longer terminal. She is imminently curable and her previous wishes regarding 'terminality' do not apply. So I must consider new options.

The 'hard' unidimensional reality has irrevocably progressed to a 'soft' multidimensionality. Her previous estimation of appropriateness of survivability is now moot. She did not want to take a chance on survival, but that isn't the way the cards fell. Now survivability is assured and removing her from life assuring machines isn't the same thing as not putting her on them initially because of her previous wishes. It is a very different concept and so I get some latitude in interpreting the new issue of survivability. Which is the most proximate force, what she wished (and authoritatively told you she wished) or what you think she might wish the second time around if her first wishes were ignored? What is a 'reasonable expectation' of what she might wish with the after-knowledge that she might survive? We chose to maintain the patient on mechanical ventilation because of new interpretations of survivability available to us after the first wish became moot.

I also think that in the multidimensional universe of critical care, there is a difference between withholding and withdrawing life-supporting technology. If a patient arrives in moribund condition and there is a living will or some other durable proof of the patient's wishes, the expectation is that death will occur as a result of those wishes. It is the whole point. The patient presumably understands that, and their considered desire is for death to occur because any outcome of a resuscitation is pre-emptively thought to be unpalatable. The outcome is known before the game starts and the patient does not desire to roll the dice because he or she doesn't want to play the game. I think it is easier for patients and their families to make decisions about withholding care because they perceive an associated outcome that is easier to accept and which makes it appear less that they are making a decision that is 'killing' the patient. If the perceived outcome is inevitable death regardless of resuscitation, then what is the big problem allowing that inevitable death to happen earlier rather than later?

Once life-supporting care is instituted however, a much clearer and impossible to ignore picture of the outcome is immediately available for the perusal of all. The patient now has options they didn't have before for survival of a sort, even if it is dependent of life support. Once this occurs, choices must be made right under the nose of that clear vision. Patients and their families are forced to look at the reality that their decisions are inextricably linked to an outcome that is no longer inevitably fatal. There are now variables that they control, and it is much easier for them to make the connection that their decision may hasten death rather than avoid prolongation of it. Instead of yielding to inevitable death, the potential now exists to manipulate death, and a large number of families find that very disturbing. That is why a large number of families demand what we consider futile life support for patients who clearly cannot benefit from it.

Leslie Whetstine

We may be able to tweak the definition of terminal and have some latitude as to its imminence, but terminality is a one way ticket. To claim that this patient was terminal one day but is now playing checkers in her nursing home after a brief stint on a ventilator is simply incongruous; it resonates as a metaphorical resurrection. I will argue that she was never terminal and the living will never entered the equation. Even if it was available on her admission, a living will of the kind described in this case was not technically in effect as per her specific criterion of terminality, thus she should have been resuscitated to the full extent of medical acumen.

The American public is already distrustful of the medical establishment, so we must consider how they will react if they think their doctors are so broad in their conception of terminality that it becomes a day to day diagnostic game. While living wills have an integral part in patient care, they risk becoming meaningless, and often problematic, slips of paper without the proper dialogue to undergird them. It is detrimental to impose a unidmensional/multidimensional spin on terminality as Dr. Crippen suggests. This type of language will most assuredly confuse the average lay

person and detract from candid communication, which is the primary reason why living wills are not proving as effective in practice as they are thought to be in theory. The communication catalyst is not there.

I agree that this patient may have in all likelihood died without an intervention, but that doesn't make her 'terminal' because that which is 'terminal' is incurable regardless of what treatments are available. Put another way, death becomes her with or without intubation if in fact she is 'terminal'. That she will certainly die without it does not absolutely mandate terminality, it renders her merely in need of an intervention. She would be terminal if the modality could not revitalize her. As a logical extension of this fact, real people in real situations may find themselves in need of a treatment without which they will die, but will not earn them the status of terminality. We cannot make the judgement of terminality by saying what will happen if something is not done. We can only make the call of terminality if death is in spite of available interventions.

For example, AIDS is currently thought of as a terminal disease. But some specific interventions now exist that will prolong the 'inevitable' death indefinitely. Therefore, we can no longer say AIDS is a 'terminal' disease. It simply requires a specific treatment without which one will die, but with which life will be extended. The corollary holds true with our case. The patient will die without a treatment that in fact exists to cure her. If you withhold it, you have committed and egregious ethical error. I am of the opinion that a physician who would have withheld intubation in this instance, as it had the ability to correct an acute situation, would have literally killed this patient in a very legal sense.

That the patient proscribed intubation if she were 'terminal' is the thorny issue for Dr Crippen. Although her living will did refuse a specific intervention that would pre-emptively save her life (intubation), it did not proscribe any interventions that would potentially save her life. Presumably she was trying to secure a fate that would not leave her on machines indefinitely or while she was trying to die. While I do not know that to be fact, I do know that her living will states that she did not want intubation if she were terminal, so whatever her motives I would abide by her wishes, all other factors being equal. But the criterion of 'terminality' as I have described it is not yet met and so Dr. Crippen's concern is irrelevant. Her living will did not convey that she would rather die than ever be intubated, she proscribed being on it if she were terminal; a process independent of the treatments available. Again we must ask ourselves how could she be irreversibly dying if all she needed was to be intubated for a period of time and subsequently returned to her baseline?

The other very large problem is the living will itself and what it was drawn up to prevent, or to secure, for this patient. Without designating a surrogate, and with merely a sheet of paper to go by, problems such as this are inevitable. The purpose of a living will is to facilitate communication. We know she did not want invasive life support if she were terminal (the definition again comes to the forefront). However, the question to be considered now is why this patient chose the rather vague language she did and why nobody (her two daughters included) really could say what she wanted.

We should not distribute living wills in a manner akin to a census form to be completed. These are life and death concerns and they should not be simply filed away on the chart without some serious dialogue. The purpose again is communication. The staff that helped her with her living will are responsible for generating discussion and ensuring that the patient understands all the implications of her decisions. The reasons behind the patient's wishes are important. It does not matter if anyone agrees with her, but being privy to her philosophy on life enables all involved in her care to understand her values. In this regard we have a communicative process and a person, rather than a pencil and a survey.

The rationality underlying the living will may be subtle, but very important. Perhaps she did not clearly understand what she meant when she agreed to refuse intubation, or, as we've seen, perhaps she did not know that terminal could mean different things to different people. Tailoring her wishes, for example acceding to a trial run of intubation if she had a reasonable chance of recovery, may have been something she would have considered (which could have been included in her living will). Lay people however, may not have insight into the mechanics of living wills or life support systems. Perhaps they do not realize that they can have total control in their care and that they can ask for help, ask questions and be as specific as they want when composing these documents.

It is not up to the public to know these things prospectively. It has become standard operating procedure upon admission to some hospitals to ask patients if they have a living will, and if not would they like to institute one, as casually as if they asked whether the patient had cereal for breakfast. It is a process which must be improved upon, and it is our job as medical professionals accept the responsibility to facilitate that process. People must be able to trust in their health care providers and to feel comfortable enough to solicit help from them when discussing such sensitive issues. Communication and trust mark a healthy relationship between patient and physician, I doubt people will be apt to trust those who are willing to classify them as terminal when they are merely in need of a routine intervention.

Mitchell M. Levy

I think this case is relatively straightforward. The patients' advance directive specifies that life support be withheld or

withdrawn when it *"serves only to prolong the process of me dying, if I should be in a terminal condition or a state of permanent unconsciousness."* Both respiratory failure and dementia fail to meet either of these two criteria. The patient does not appear to have any disease that could be considered, by conventional definition to be 'terminal'. One could make the case that the patient will certainly die if nothing is done, and therefore respiratory failure itself meets the criteria for 'terminal'. I do not think most clinicians or patients view the concept of 'terminal' in such a narrow, immediate sense. For most of us, 'terminal' refers to a patient with chronic, end-stage disease, who is close to death and without a reasonable chance for reversal. I do not think that the patient met the criteria for the living will on admission to the ED. If terminal were to be interpreted in such a narrow sense, then any serious illness could be seen as 'terminal', in which case the patient would not have made her request for withholding or withdrawal, conditional. In addition, even if there were a consensus amongst the family, the patients' advance directive specifically prohibits surrogate medical decision-making. One could argue that the patient, when competent, did not want any member of her family to make medical decisions for her. In this case, the clinician must continue life support and begin a process of conflict resolution within the family in an attempt to better understand who, if anyone, understands the needs and wishes of the patient. My recommendation would be that life support be continued and further investigation be pursued with the family, primary care physician and nursing home staff.

Robert Truog

While I have great respect for the other commentators on this case, I think their focus upon trying to define 'terminal' is misguided. It reminds me of the efforts a decade ago to come up with a definition of "futile'; efforts that have become paradigms of futility themselves. The solutions here will inevitably be found in procedures, not definitions.

So, to begin with, it is helpful to recognize that advance directives come in two flavors; living wills and durable powers of attorney. Ideally, these two should be used together. The purpose of a living will is to give families and clinicians some idea about how a patient would like to be treated under various clinical scenarios. In this case, the patient indicated that if she was terminally ill or in a state of permanent unconsciousness, she explicitly did not want any of the life-sustaining treatments that she listed in the document.

While neurologists have a pretty good handle on how to diagnosis the permanent vegetative state (that is, permanent unconsciousness), the definition of 'terminally ill' is (and I believe will remain) hopelessly elusive. All of the definitions that might be proposed depend upon a number of assumptions, and we have no way of knowing what assumptions this patient might have accepted or refused. This is why living wills should always be coupled with a durable power of attorney. The surrogate decision-maker appointed by the durable power of attorney is specifically charged with the job of interpreting the patient's living will, and determining (within reasonable limits) whether the patient's current clinical situation meets the conditions specified in the living will. Physiologic observations like those of Dr. Crippen, while quite sophisticated and interesting, miss the mark because he is not the one authorized to interpret what the patient meant when she filled out her living will.

In this case unfortunately, the patient specifically declined to appoint a surrogate decision-maker. Furthermore, the two most reasonable candidates for this role are relatives who are in disagreement, and there is no way for the clinicians to know which of the two relatives can most accurately represent the patient's interests and desires. For these reasons, I see no alternative but to ask the court to appoint a guardian *ad litem* for this patient. The primary responsibility of the guardian would be to fulfill the role of surrogate decision-maker, that is, to interpret the patient's living will and to apply it to the patient's current clinical situation.

If the guardian were to determine that, at the time of presentation, the patient would not have wanted to be intubated and mechanically ventilated, then the fact that she subsequently received those interventions and improved is entirely irrelevant. Those who would argue otherwise make a serious logical mistake. For a patient to rightfully refuse a medical intervention, it is not necessary for that intervention to be futile. Indeed, the strength of the patient's refusal arises explicitly from the fact that the intervention may, in fact, be very effective at restoring the patient to a baseline state of health. Nevertheless, the patient has determined that the burdens associated with the intervention exceed the value of this benefit.

In other words, the fact that this patient improved following intubation and ventilation is neither clinically surprising nor ethically relevant. The purpose of the living will is to indicate the conditions under which the use of life-sustaining treatments is judged to be more burdensome than beneficial, even if these treatments may be effective. If a court appointed guardian were to determine that she would not have wanted to be intubated and ventilated at the time of her presentation, then she should be immediately extubated and made comfortable. To do otherwise would be to misunderstand the meaning and purpose of living wills.

Conclusion

John Luce

In the United States and other technologically sophisticated countries, patients are requesting like never before

that physicians respect their wishes for or against life-sustaining therapy. At the same time, physicians are increasingly willing to honor such requests, especially when their patients' wishes seem well thought out. Living wills and similar written instructions provide a means by which patients can articulate what they want done in the event of critical illness, whereas devices such as the durable power of attorney for health care allow patients to designate surrogates to act on their behalf. Ideally, written instructions are sufficiently detailed to cover a variety of clinical circumstances, and the designation of surrogates leaves no doubt as to whom will represent the patients' interests. Furthermore, as Robert Truog stresses, both kinds of advance directive should be used in concert so that surrogates can call upon written instructions to specify what patients would want done.

The case under discussion is an example of how not to prepare an advance directive. It concerns an elderly woman who has filled out a living will that sanctions withholding and withdrawal of life support only is she is "in a terminal condition or a state of permanent unconsciousness" but includes no other medical situations. In addition, the patient has refused to name a surrogate "to make treatment decisions for me if I shall become incompetent," which she has become. When the patient develops respiratory failure due to a pneumonia that she might survive, the emergency department physicians to whom she is brought have no choice but to intubate and mechanically ventilate her. These interventions are required because the patient is not yet terminal or permanently unconscious and because her two daughters, neither one of whom is her official surrogate, disagree about how their mother should be managed. Only if and when the patient fails to respond to treatment can the physicians who will care for her in the intensive care unit recommend limiting life-sustaining therapy. As Dr. Truog suggests, a court-appointed guardian must make the final decision regarding withholding and withdrawal of life support from the patient even if her daughters resolve their differences, because she has specifically excluded them from being her surrogates.

Clearly, physicians should discourage patients from making advance directives of the sort made by this woman. More important, physicians, particularly those who serve in a primary care capacity, should encourage patients to prepare directives that simultaneously detail their wishes and designate surrogates to represent them. Although advance directives may be made on hospital admission, they should be prepared before critical illness occurs if possible. Furthermore, as Leslie Whetstine observes, the directives should stem from a patient-physician relationship founded on communication. Physicians who have fully discussed the future with their patients are in the best position to facilitate end-of-life care for them.

Authors' affiliations: David Crippen (University of Pittsburgh Medical Center, and Department of Emergency and Critical Care Medicine, St Francis Medical Center, Pittsburgh, Pennsylvania, USA), Mitchell Levy (Department of Critical Care, Rhode Island Hospital, 593 Elly St, Providence, Rhode Island, USA), Robert Truog (Multidisciplinary Intensive Care Unit, Children's Hospital, Farley, Boston, Massachusetts, USA), Leslie Whetstine (Medical Ethics, Duquesne University, Pittsburgh, Pennsylvania, USA) and John Luce (Division of Pulmonary and Critical Care Medicine, San Francisco General Hospital, 1001 Potrero Avenue, Room 5 K1, San Francisco, CA 94110, USA)

Note: All authors contributed equally to this article