

Are Advanced Directives Relative? The Ethics of Surrogate Decision Making

Ramy Sedhom*

Department of Internal Medicine, Rutgers Robert Wood Johnson Medical School, New Brunswick, NJ, USA

*Corresponding author: Ramy Sedhom, Department of Internal Medicine, Rutgers Robert Wood Johnson Medical School, New Brunswick, NJ, USA, Tel: 19178164858; E-mail: sedhomr@gmail.com

Received date: December 06, 2016; Accepted date: December 21, 2016; Published date: December 28, 2016

Copyright: © 2016 Sedhom R. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited

Abstract

An important aspect of medical ethics is the right to decline medical treatment. A problem is how to honor the wishes of patients who lose their voice and can no longer accept or refuse medical treatment. Although advanced directives are attempts to protect autonomy, decisions are not immutable and may be negotiated by family, loved ones, and other surrogate decision makers. Describes is a case that underscores the importance of advanced care planning, the complexity of decision making, and area for potential improvement.

Keywords: Ethics; Surrogate; Decision making

Introduction

One of the fundamental rights of patients is the autonomy to decline medical treatment. An advanced directive attempts to put into writing these wishes with the hope that they would be followed when patients become incapacitated. When I had started as a medical intern, I had believed that these wishes were definitive and absolute; however, many families modify these preferences when acute illness arises. I have struggled with this concept from an ethical standard, especially when altered decisions lead to burdensome illness before death.

Mrs. Smith, whose named has been changed for privacy purposes, was an elderly woman, well into her 80s, with diabetes, hypertension, hyperlipidemia, peripheral vascular disease, heart failure, and chronic obstructive pulmonary disease. She was my clinic patient and has been followed for many years in our resident practice. Her daughter always brought her to her appointments, and waited politely in the waiting room while her mom saw the doctor. One day, Mrs. Smith presented acutely ill. We recommended she be transferred to the emergency department. Prior to transfer, we reviewed our records and noted her advanced directive. We confirmed her prior stated wish that resuscitation not be attempted and that she must be allowed to die a natural death. Her Physician Orders for Life-Sustaining Treatment (POLST) form was printed and sent with her via ambulance.

In the emergency room, Mrs. Smith was diagnosed with septic shock. The emergency room physician asked the family for permission to intubate. Her daughter agreed. All were aware of the patient's previously documented wishes. When the patient became obtunded, she was intubated and admitted to the Intensive care unit (ICU). A family meeting was held the next morning. The ICU staff and hospital ethics committee discussed the overall goals of care. The family insisted on full treatment, with full attempts at resuscitation. Five days later, they agreed to hemodialysis. After two weeks in the intensive care unit, with multiple organs failing, they agreed to comfort care. After being taken off the ventilator, she died peacefully the same day.

I recall seeing Mrs. Smith in clinic early in my intern year. She was well put together and had a smile that would brighten my day. Despite her good mood, she appeared frail. I had noticed she had trouble

getting up on the exam table the second time I had seen her. After spending my first month of residency in the intensive care unit, I had an appreciation for goal setting prior to acute illness. We had filled out a POLST form together. Mrs. Smith had mentioned in several encounters over the year that she would not want to live on a breathing machine. Quality of life was important to her. She had mentioned that if she was not well enough to walk to church on Sunday, it was a sign for her to be with God. We completed her do not resuscitate/do not intubate [DNR/DNI] forms.

Speaking to the primary team in the intensive care unit, they felt that they were violating Mrs. Smith's wishes regarding treatment. Her wishes in clinic were of a sound mind and were reiterated at multiple visits. The daughter was absent during these discussions. To her, early in the ICU course, she believed that the directives were abstract and that her mom did not know the implication of her decision, especially in the case of reversible illness, such as infection. For her, it was her duty to care for her mom and protect her from death.

As a resident interested in issues regarding end of life, I have been intrigued by a study that described several problems between physicians and surrogates [1]. The emergency physician, who was signed out her advanced directive from the outpatient clinic, must have interpreted her case as falling in the gray zone. Like the daughter, he likely found it difficult to stand there and watch the patient expire. "Just a few days of life support." To echo one of the physicians I trained with, "I am here to save lives and make people better, it's hard to swallow a DNR."

So, is it allowable to make an advanced directive a 'relative' decision? To me, it shakes the moral standard of autonomy, but this has not been an isolated incident in my three years of training. We all come with our own cultural and religious backgrounds, education, and personal beliefs. To what extent does this influence our decision making? Looking back, was this a bad decision by the daughters? Was it a bad decision by the emergency room physician? And was it bad because of its poor outcome? Or bad because it is ethically wrong? The enormity of seeing a loved one die is overwhelming. Surrogate decision makers aren't trained to make big decisions, is it truly an informed decision to begin with?

Advanced directives are a formal attempt to protect a patient's voice when they are no longer autonomous. It assumes that these decisions are precise and absolute. It also assumes that they are well known by loved ones and most importantly, surrogate decision makers. This assumption can lead to unfortunate scenarios as briefly described in this case and raises an important area of improvement and future policy development. The role of the family is underutilized in routine discussions of advanced directives. Physicians should be keen to share with patients how influential family members can be when implementing advanced directives and misunderstandings certainly lead to no adherence to patient's wishes.

Outside the hospital, I believe that we had done things right, but missed an opportunity to connect with her daughter. We planned in advance, had the difficult conversations, and relayed her wishes to the emergency room physicians. Her situation, like many others, was clear – small chance of survival, large chance of suffering. Despite this, her preferences were not granted. She was intubated and died in the intensive care unit. Had her daughter been included in prior planning, a collaborative decision might have been more likely to be honored. If the patient was not willing to include her daughter in the initial conversation, she should have been encouraged to share the specifics of her decision and to share it with important surrogate decision makers.

In the weeks after her death, I struggled with end of life conversations, including advanced directives and designation of health care surrogates. I am now trying to involve families regularly in goal setting conversations, but still do not have a clear understanding of when it is permissible for non-adherence to patient wishes. There is limited training directed towards medical students and residents in end of life in general, and almost none on how to communicate with surrogate decision makers. Can we do it better?

For now, I've learned that if family members are not included in discussions, patients should be encouraged to share their wishes with loved ones. This would limit potential for misunderstandings and potentially decrease the amount of post-traumatic stress related to decision making at end of life. I hope to continue having these conversations in the outpatient and to find ways to improve misunderstandings of the intent of establishing advanced directives. Many terminal ill prefer decision making to include their physician [2]. Though I humbly accept the limitations of advanced directives, I do hope to see a change in medical education to address shortcomings in such a sensitive area of patient care.

Physicians should engage in preventative ethics by talking about advanced directives for all life-limiting disease and by asking patients who should speak for them in the event they are unable to speak for themselves. Families should similarly be educated about the role of surrogate decision making and be more integrated into advanced care planning early in the disease course. Addressing the broader trajectories of chronic illness can limit cognitive and emotional burdens for families and loved ones, providing them with clear information that is unambiguous. It also gives them time to process that information and ask additional questions if they need to. This will allow our medical system to truly be there for our patients when help is needed most. It is our ethical duty to do so.

References

1. Miles SH, Koepf R, Weber EP (1996) Advance end-of-life treatment planning. *Arch Intern Med* 156: 1062-1068.
2. Sulmasy DP, Hughes MT, Thompson RE (2007) How would terminally ill patients have others make decisions for them in the event of decisional incapacity? A longitudinal study. *J Am Geriatr Soc* 55:1981-1988.