Healthcare Decision Making for Dementia Patients: Two Problem Cases

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Abstract

In a culture, such as ours, that reveres autonomy, the issue of when patients should be allowed to make their own healthcare decisions has received increasing public scrutiny over the last few decades. The recent emphasis on leaving directives to make decisions in advance, so to speak, has complicated this issue. This article contains a discussion of two cases which are problematic for the issue of healthcare decision making due to the lack of general competence of the patients along with the seriousness of the decisions in question. This discussion is followed by a proposal of a method to be used in deciding difficult cases where advance directives are involved, as well as an evaluation of and solution to the two problem cases.

INTRODUCTION

Who should make healthcare decisions for a patient? Under ideal conditions, the patient, of course, should make his or her own healthcare decisions. The idealized image that comes to my mind regarding healthcare decision making is of the competent and conscientious patient who exercises her autonomy by rationally considering her treatment options and choosing, after consultation with her healthcare professionals, the option which is best for her. But real life is, unfortunately, messy and real cases usually don't conform to these ideal circumstances. Sometimes when healthcare professionals are faced with a patient, the question of who should make her healthcare decisions does not have such a clear answer, often because the patient's very ability to make such a choice is questionable. At times, the life of a patient hangs in the balance, and whether she lives or dies depends upon who gets to make her healthcare decisions. We will examine two such “messy” cases in which it is initially unclear who should decide the fate of the patients in question by making their healthcare decisions. After this, I offer a four-step criteria for deciding who should make such healthcare decisions and then apply the criteria to the cases at hand.

TWO CASES

It is often very easy for healthcare professionals (HCPs) to determine when a patient is capable of giving consent for a medical procedure. Indeed many HCPs have excellent intuitions regarding the ability of a patient to consent to a simple procedure and they needn't rely on anything further for making such determinations of a patient's capacities in many cases. In the following two cases, however, such a determination is not so simple. The following individuals' competency status, as well as their continued identity through time, is questionable due to illness. Both patients have expressed contradictory wishes at different times, leaving their healthcare professionals and families to decide which instructions to follow. Further, assuming the present time (the time at which treatment is required) is t_2, the general competence of each of these individuals at t_2 is questionable. Thus, each of these cases present problems for the HCPs involved, and the families of the patients, who need to decide treatment for these individuals.

These cases make an excellent starting point for a discussion of workable criteria for assessing who should make healthcare decisions since, in each case, it is necessary to consider whether the patient's wishes at some particular time t_1, when each expressed their desires regarding future medical treatment and when each was presumed competent, take precedence over their current or most recent imperatives regarding treatment, at time t_2. Whether or not each patient remains the same person at t_2 as they were at t_1 obviously has implications for such decisions, as, of course, does their status as persons and their competency status.

These cases are real. Unfortunately, the cases are underdescribed in the literature to fully suit our purposes. As such, I have had to make assumptions about certain features

that may or may not be factual. These assumptions are based primarily on the symptoms exhibited in light of the illnesses or impairments from which the patients in question suffer. I have tried to make note of such assumptions where they occur.

CASE #1

Daniel is a 90-year-old man who has recently been admitted to a short-term, in-hospital nursing facility for the elderly because he has been exhibiting signs of dementia along with behavior problems. Daniel's dementia has been leading to difficulties with eating and drinking. He is unable to swallow food or drink without getting them into his lungs. Daniel is in good health otherwise and has no terminal diseases and seems relatively happy. His behavior problems have been easily controlled with medication and he enjoys watching TV, reading (more or less) the newspaper, and talking to people. By all accounts he is relatively happy and content with his surroundings, except for his eating problems. The doctors have decided that the only way to feed Daniel effectively is to insert a feeding tube into his stomach.

Several years ago, Daniel signed a living will indicating that nothing extraordinary should be done to keep him alive if he were ever in such a state that he could not competently consent to treatment. This living will apparently precludes the insertion of a feeding tube. The doctors, in consultation with Daniel's family, have decided that he will not be given nutrition and hydration since they feel this would violate the intent of his living will. Daniel has not been given food and water for several days, although he has constantly complained of being hungry and has asked why he hasn't been given any food. He cannot currently remember having signed a living will and legally lacks the competence to change such a document. He does not, however, currently wish to starve to death and has repeatedly expressed the desire to stay alive, even if it means being intubated, although it is certainly unclear whether he can understand what being intubated would entail.

Daniel's family and HCPs are thus faced with the decision of whether to intubate him or allow him to die. At t_1, a presumably competent person signed a living will generally forbidding such a procedure. At t_2, a seemingly incompetent patient appears to want the procedure, although it does not appear that he fully understands what it entails, nor does he presumably understand why it will help him not feel hungry any more. The patient at t_2 does seem to be enjoying his life because by all accounts he is relatively happy most of the time, even though his cognitive capacities are severely limited. His family, who are typically called upon to make his healthcare decisions for him, wish to refuse the procedure.

Should Daniel be intubated?

CASE #2

In 1990, Dr. Gerald Klooster (of California) was diagnosed with Alzheimer's. In November of 1995, Dr. Klooster's case sparked a public controversy over physician-assisted suicide when his son, Dr. Gerald “Chip” Klooster II (of Michigan), decided his father's life was in danger and spirited him from his parents' vacation in Florida to his own home in Michigan. Chip argued that his mother, Ruth, was plotting with the infamous Dr. Kevorkian to end Jerry's life. Several years, many court cases, and one failed suicide attempt (by Jerry) later, Jerry was returned, under supervision, to the care of Ruth and one of their daughters.

Given the involvement of the infamous Dr. Kevorkian and the current debate over physician-assisted suicide, the Klooster case has received quite a bit of media attention. The points of this case which are of interest to us, however, revolve around Jerry's identity through time, his personhood, and his competency. Unfortunately, many of these details are unclear. As such, I have filled in some of the blanks with the most reasonable assumptions.

Ruth Klooster admits that she had a discussion with Dr. Kevorkian about Jerry, at Jerry's request. Assuming that it was Jerry's decision to contact Kevorkian and that Jerry's suicide attempt was legitimate [3], we can conclude that Jerry wanted to die, at least at two points during his illness (namely, when he requested a consultation with Kevorkian, and when he attempted suicide). We might further assume, as Chip argues, that he does not now fully understand what it means to commit suicide and that he no longer has the capacities and physical abilities to reason through and commit suicide on his own. We can also assume that Jerry wished to not be kept alive on a machine if it came to that (he had signed a living will stating this years ago when he was presumably competent).

Setting aside the controversy over the moral and legal permissibility of physician-assisted suicide, should Jerry be allowed to “visit” Dr. Kevorkian? In other words, can Jerry take part in a physician-assisted suicide in his current debilitated state? To answer such a question, we need to

determine whether Jerry remained the same person at t_2 (now) as he was at t_1 (when he signed his DNR and requested to see Dr. Kevorkian) and t_1' (when he attempted suicide). Answering such a question obviously also requires an assessment of his competency and status as a person at t_1, t_1', and t_2. We will assume that Jerry is in the late stages of Alzheimer's at t_2, that he was in a middle stage at t_1', and in an early stage and unquestionably competent at t_1.

It is unclear whether Jerry currently, at t_2, wishes to die. We shall assume then that his current wishes at t_2 regarding physician-assisted suicide are ambiguous, although his wishes at both t_1 and t_1' are clearly in favor of physician-assisted suicide. Should Jerry be allowed to die?

Do Daniel and Jerry currently meet the conditions necessary for personhood at t_2? I will assume without argument that each is a person at t_1 since each enacted an advance directive at t_1 regarding future treatment. Because competency is required for advance directives, it is plausible to assume that each of them was judged competent by their HCPs or lawyers or family members at t_1. So we'll assume each is a competent person at t_1 and that each expressed clear, albeit general, wishes regarding future treatment if ever in a state of being unable to give consent for himself.

THE FOUR-STEP PROCESS FOR DECISION MAKING

Who gets to decide the fate of Daniel and Jerry? I feel the best way to handle these cases is through the following schema for deciding who should make healthcare decisions for patients in general.

Step 1: Is the patient in question (P) currently specifically competent to make a choice regarding the healthcare decision (D) in question?

--If yes, the decision made by P should stand if there are sufficient resources [4] to honor P's wishes.

--If no, move on to Step 2.

I would argue that the competence required of a patient to make a decision about his or her care is situation-specific. The more serious the consequences of the decision, the higher the degree of competency required. If a patient wanted to forgo a simple and virtually painless procedure with minimal negative side effects, the refusal of which would end the patient's life, a high degree of competency would be required to allow the patient to make such a choice. On the other hand, a generally incompetent patient, one with severe dementia, for example, may be competent to make a simple decision regarding their care, or at least to express their preferences.

Is Daniel competent to consent to the insertion of a feeding tube to save his life? Such a tube would be somewhat invasive yet entails a relatively simple procedure with a high chance of success. The consent necessary for agreement to simple life-saving procedures requires a minimal level of competency; namely, P needs to be a person and make an understandable expression of his desire to stay alive. It seems uncontroversial to claim that Daniel is a person since he can communicate thoughts and exhibit some basic reasoning, even if his mental capacities are severely impaired. However, it is unclear whether Daniel can appreciate that his quality of life may be very different after the procedure. So Daniel can express the desire to stay alive although he probably can't understand the consequences of such a request. If Daniel possesses the minimal degree of competency necessary for his decision then the presence of an advance directive forbidding such a procedure is irrelevant. We will reserve judgement on the question of his competency until we have examined the other issues involved. At the very least, however, Daniel's preference to stay alive should be considered here.

Is Jerry competent to consent to physician-assisted suicide? Unfortunately, Jerry's wishes are unclear regarding the choice of this option. Since he would need to be able to at least understand the option and make a definite choice in favor of it, Jerry is not currently competent to request PAS. Unlike choosing to stay alive, choosing to end one's life requires a very high degree of competency in the form of understanding one's choice and expressing personal preferences in a logical manner.

Step 2: Does P have an advance directive that stipulates a situation relevant to D?

--If yes, move on to Step 3.

--If no, move on to Step 4.

This step is simple enough. By ‘advance directive' I intend any sort of legally binding directive such as a living will or a durable power of attorney. It seems that both Daniel and Jerry have such a directive.

Step 3: Is the advance directive binding? That is, does it meet the following criteria?

1- It was legally made by a generally competent person and the directives are directly relevant to making D.

2- If P is currently a person, then the person who enacted the advance directive is the same person as P and following the guidelines of the directive does not create a conflict with P's current or most recently expressed wishes.

3- If P is currently not a person, then the person who enacted the directive was the last competent person to inhabit P's body and fulfilling the directive would not be unreasonable. [A patient who is not and will never again be a person has no interests to maximize]

--If either 1 and 2, or 1 and 3, are met, then the advance directive will stipulate the appropriate choice for D.

--If neither 1 and 2, nor 1 and 3, are met, then move on to Step 4. The advance directive cannot stipulate an option for D if this is the case.

This step is rather complex in that it may require an assessment of personhood and identity through time as well as a determination of what is in the best interests of a particular patient.

If Daniel were to be judged incompetent to make his decision to stay alive, should his directive decide his care? Although we don't know much about the specifics of his directive, his family and HCPs felt that treating him would violate the "intent" of his directive. I would assume from this that his directive does not specifically mention the procedure in question although it probably rules out using extraordinary life-sustaining treatments in general in his current condition. Although the procedure in question does not appear to be extraordinary, let's assume for the sake of argument that his directive does meet criterion 1 - does it meet #2 or #3? Criterion 2 would be relevant here since Daniel is a person. I don't think Daniel's directive meets this criterion since an identity claim linking the signer of the directive to the current Daniel is not justified and, as we have previously noted, demented Daniel's death by starvation does not seem to serve his best interests.

Jerry has a DNR order but his advance directive does not make provisions for a physician-assisted suicide. His case, therefore, fails to meet criterion #1; that is, it is not directly relevant to the decision in question. We must look to Step 4 to decide Jerry's case.

Step 4: What option of D would be in the best interests of P? If P lacks interests because P is not a person, then what are the wishes of family and friends? Does P have the potential for future interests?

--If the other steps have failed to give us an answer, then whatever option is found to be in the best interests of P, given that P is a person, should be followed. In this situation, P is allowed, if possible, to make his own determination of what is best for him. If P is not a person (in the sense of having and communicating thoughts and exhibiting basic reasoning) but has the potential for future interests, if P is a infant for example, then P's future interests along with the wishes of P's family and friends should be the deciding factors. If P is not a person and in all likelihood has no future interests, a PVS patient for example, then the judgement of P's family and friends, if reasonable, should stand.

Recall from the last chapter that the determination of a patient's best interests may rely heavily on the judgement of family and friends if P is generally incompetent.

What is best for Daniel? In his present state, it seems that being kept alive would be in his best interests since his quality of life is acceptable to him. After being intubated, however, this may change. But it would be problematic for HCPs to allow a patient to die, against his wishes, because they are unsure if he can handle the quality of life which may ensue. Daniel should be intubated, in accordance with his preferences at t_2, and then his interests should be reassessed to decide whether treatment should continue.

Jerry's best interests are clearly a topic of debate between his wife Ruth and his son Chip. It may, therefore, be necessary in this case to look beyond Jerry's family and friends for a determination of his best interests. From all accounts, Jerry's current quality of life is not poor. Although his disease is unpleasant, there are no reports that he is currently in pain or constantly agitated or generally unhappy. And since he currently isn't expressing any concrete wishes to be euthanized, there is no reason to believe his quality of life is so bad that to him it is not worth living. Jerry's treatment decision should be made by this consideration of his best interests. He should not be euthanized.

References

1. This case is adapted from Gowans A. The Third Age. Columbia Daily Tribune 1999 Feb 8;Sect. B:3.
2. This case was featured on the television news program Dateline NBC in 1996 and 1997.
3. These are somewhat questionable assumptions because Chip Klooster argues that the "suicide" attempt, which included 60 sleeping pills washed down with Jack Daniels

whiskey, was orchestrated and carried out by his mother, since, Chip argues, his father could not have done it alone.

4. The issue of allocating resources is too large to tackle here. Whatever method is used by the healthcare facility in question should be sufficient.

Author Information

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