

Justified Paternalism: The nature of beneficence in the care of dementia patients

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Abstract

The issue of patient autonomy in cases of permanent dementia has recently received a great deal of philosophical attention. Specifically, many have worried about ethical issues surrounding advance directives in which people specify how they shall be treated when they are no longer competent to make their own medical decisions. Ronald Dworkin has been a staunch defender of what he calls precedent autonomy in these cases, believing persons have a right to control, to some degree, how their lives will end, despite the common intuition that the principle of beneficence requires us to improve the experiential quality of patients' lives. Objections have been brought against Dworkin on a number of fronts, including worries about personal identity theory and informed consent. Here, I offer an objection to Dworkin's assessment of the nature of paternalism as it relates to cases of permanent dementia.

Introduction

Traditional bioethics holds respect for patient autonomy as one of its basic guiding principles. Some patients however, are considered medically incompetent and are not permitted to make decisions about the course of their medical care. These groups typically include children, some developmentally disabled individuals, and some individuals with advanced dementia. Each group has special characteristics that will lead to unique ethical principles designed to guide medical decision-making, but they each present a similar problem. When one person is, for some reason, not able to exercise autonomy over a certain area of life, a rational individual or group of rational individuals must take on the responsibility to make decisions in the person's best interest. There has been some question as to who should make these decisions, but the most controversy arises in the latter case of dementia. Ronald Dworkin has weighed in on this issue, arguing that individuals who don't yet have dementia should be their own future guardians through the system of advanced directives. Rebecca Dresser has explained a number of objections to Dworkin's theory. I will examine Dworkin's

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argument, Dresser's objections to it, and then present my own objection to Dworkin.

Both Dresser and Dworkin consider the case of Margo, a hypothetical person based on an actual case. Margo is a patient with dementia (not medically competent) who seems quite happy to outside observers, but who signed an advanced directive saying she would prefer to be allowed to die once afflicted with dementia, should she need life-saving medical treatment.

In Ronald Dworkin's 1993 book, *Life's Dominion: An Argument about Abortion, Euthanasia, and Individual Freedom*, he argues that (competent) individuals should be allowed full authority to determine what the course of their lives shall be if they somehow become incompetent (Dworkin, 1993, p. 226). In other words, healthy individuals should be able to create documents with explicit instructions for what healthcare providers should do in specific instances which could not ethically be breached in most cases regardless of their own future expressed desires. He supports this conclusion by prioritizing what he calls a person's "critical interests," or meaningful life goals and projects, over "experiential interests," or desires to have enjoyable experiences, even if the individual is made unaware of her critical interests (Dworkin, 1993, p. 230). According to Dworkin, people should be granted the autonomy to pursue the kind of death they feel fits in with their life story and the character they have cultivated throughout life. Competent individuals, as opposed to experts who claim to know what is in the best interests of persons, should be able to decide for themselves what they want in a future situation because we value the "integrity view of autonomy," the view that persons should be granted the freedom to make choices that are their own, even if they may not in fact be in their best interest (Dworkin, 1993, p. 224).

Although it may appear to even highly experienced psychologists that Margo is still enjoying life to some degree given the fulfillment of her experiential interests, Dworkin would argue that her living with dementia is necessarily opposed to her own critical interests (that she had while competent) and therefore undermines any quality of life she might have even though she is not nor will ever again be aware of those critical interests. According to Dworkin, this treatment ignores the basic bioethical principle of beneficence, because those caring for her are not making decisions that comply with caring for the whole person (which to Dworkin includes her previously expressed wishes) or that lead to the fulfillment of her critical interests

(Dworkin, 1993, p. 231).

In her article “Dworkin on Dementia: Elegant Theory, Questionable Policy,” Rebecca Dresser makes a number of objections to Dworkin’s suggestions about advanced directives and dementia patients. Many of these objections are empirical or practical in nature, while others are theoretical. My interest here is more in the theoretical objections, though the others are worth noting as well. For example, Dresser wonders if in fact Americans do generally place a high value on how they die and whether the integrity of their characters is maintained through the end of life. Additionally, she worries that people do not have sufficient knowledge of the course of dementia and what the experience of a dementia patient is like, and the advance directives will not be specific about when during the course of the disease the person wishes to stop treatment (Dresser, 1999, p. 52).

One of Dresser’s large concerns is that persons may not be able to accurately predict what dementia will be like and whether it would be acceptable for them to live in such a condition (Dresser, 1999, p. 52). In fact, competent persons often have trouble imagining themselves with any sort of disability (including physical disability); compared with imagined satisfaction with disabilities among the non-disabled, satisfaction is quite high among competent physically disabled individuals. Dresser’s concern is that the same discrepancy might exist between competent people and those suffering from dementia, if we accurately measure the satisfaction of the latter group. Dworkin would be able to dismiss this concern on two accounts. First, he acknowledges the epistemic problem of measuring the satisfaction of dementia patients by saying that although we cannot know the level of satisfaction of a dementia patient, the best person to judge this is the same patient while she is still competent (Dresser, 1999, p. 49). Second, the conscious satisfaction of the dementia patient, even if it could be accurately assessed, is of little importance no matter how high it may be. What matters to Dworkin is that the critical interests of the person have been compromised simply in virtue of the fact that she is living with dementia. Because Dworkin’s argument rests on the premise that one’s interests can be meaningfully neglected without the person’s knowledge, Dresser’s worry here is not an adequate objection.

Another concern Dresser raises is the issue of whether identity persists through drastic changes in an individual’s character and personality. If identity does not persist, a competent individual designing an unalterable advance directive would be making the decision to place a different future person into a binding contract based on her own desires and worldview. No reasonable system of ethics allows for this sort of practice (Dresser, 1999, p. 52). This is a common objection to Dworkin’s argument, and is very troubling in light of predominant contemporary views

of personal identity holding that “psychological continuity is (at least) a necessary condition for personal identity” (Buchanan, 1988, p. 280). Dworkin’s case rests on the dubious falsity of this claim. However, given Dworkin’s commitment to strong personal freedom, it seems he would not be worried by such a concern; this is not his view of personal identity. Furthermore, Dworkin would say that the primary reason for having advance directives for dementia at all is the inability of dementia patients to make competent decisions about their medical care. Someone, or some group of people, needs to make medical decisions for the person with her best interests in mind. Dworkin believes that, more than any doctor, counselor, or family member, the decision should be left to the pre-dementia individual to which this treatment will be given (or withheld). Despite the fragility of Dworkin’s argument given the debate surrounding personal identity, his argument is still open to objection even if he is granted his assumption that identity persists throughout dementia.

Dresser’s objections will not worry Dworkin because the two philosophers fundamentally disagree on basic assumptions about dementia patients. I will present an additional objection to Dworkin that does not appear in Dresser’s work. Dworkin is very much worried about paternalism. He mentions that not allowing Margo’s stated wishes to be carried out would be an “unacceptable form of moral paternalism” (Dworkin, 1993, p. 231), implying that he sees some forms of paternalism as acceptable. Moral paternalism is acceptable in cases in which it enhances the future fulfillment of critical and experiential interests of a temporarily incompetent person or in some cases in which it enhances the future fulfillment of a permanently incompetent person’s experiential interests. Temporary incompetence includes childhood (in which there is focal incompetence for certain kinds of decisions) and altered states (that are related to sleep or mind-altering substances). Permanent incompetence includes dementia (and other neurological diseases) and cases in which developmental disabilities render persons focally or completely incompetent to make decisions for their well-being.

I wish to make a distinction regarding my objection to Dworkin’s views of beneficence and autonomy in these cases. Others, most notably Seana Shiffrin, have contested Dworkin’s assumption that whatever the dementia patient should express should be ignored in making decisions about her care. For Dworkin, the dilemma is between respecting the wishes the patient expressed while competent and giving agency to caretakers, family members, counselors, and physicians. Shiffrin takes this to be a false dilemma, making an analogy between the permanently demented and terminally ill children. She notes that our intuition is to respect the expressed desires of terminally ill (but not yet fully competent) children insofar as these wishes are not dangerous even though we cannot claim we are

helping the children to develop their autonomy (Shiffrin, 2004, p. 206). I do not take this case to be analogous to the permanently demented, and do not wish to challenge Dworkin's assumption that the apparent expressed will of the permanently demented be ignored. Except for the very young, children have a higher degree of competence than the seriously demented and can be expected to retain this competence until death. Additionally, because these children have greater access to their memories than the permanently demented, they are able to engage in developing meaningful life projects, even if to a lesser extent than competent adults. Our intuitions in the case of terminally ill children should not inform the argument about permanently demented adults.

In *Life's Dominion*, Dworkin makes an analogy between permanent dementia and temporary incompetence using the example of a Jehovah's Witness who asks in advance not to receive a blood transfusion even if he pleads for one when it becomes a medical necessity (Dworkin, 1993, p. 227). I do not find this example to be as obvious as Dworkin intends it to be, but another analogy will suffice in leading to the same end. If, as a student, studying keeps me awake until quite late, I might ask a friend to wake me up in the morning and be sure I leave for work on time. I might say something like: "I know I'll be temporarily incompetent in the morning, and I'll tell you I don't want to get up and possibly try to convince you that I don't need to go to work. No matter what I say or do then, carry out only the instructions I give you now, for they are derived from what I actually want." My friend would be obligated to do as I say, ignoring whatever desires I seem to have in the morning, knowing that paternalistically getting me to work is the best way to maximize the fulfillment of my critical interests that I may temporarily be unaware of. In other words, heeding my previous orders is required by beneficence. Dworkin would say this example is analogous to advance directives, but I will show why it is not.

My friend's use of paternalism by ignoring my apparent current interests and acting only on my previous orders in order to get me to work in the morning is permissible because I am temporarily unaware of what my critical interests are, or I am temporarily unable to use my rational capacities to act in ways to maximize the fulfillment of those interests. After becoming fully conscious, I will once again be fully aware of my entire spectrum of interests and will be competent enough to make decisions to those ends. The justification for paternalism in these cases rests upon the future competence of the individual. There is no reason to promote critical interests that a person cannot ever possibly be aware she has. Our only obligation is to act to maximize the fulfillment of the incompetent person's current and future interests as far as we can tell what they are, which in the case of dementia can only include experiential interests. The paternalism used in caring for a dementia patient

and ignoring her now vacant critical interests is, in fact, acceptable. This is not to say that the advance directive is not evidence of the patient's previous critical interests at the time it was signed. It is evidence that these interests existed, but is not sufficient for proving they still exist. If any critical interests about Margo's life still exist, it is only because other people now hold them, just as people might take on the critical interests of the dead as their own to ensure the completion or continuation of the projects of a deceased person.

Given Dworkin's strong commitment to personal autonomy and narrative coherence in one's life, he might give another analogy to show why I am mistaken. Suppose a competent person has the critical interest of raising her children in a manner so that they will flourish. Now suppose the children are adults who have moved away and only see the parent rarely and communicate via telephone. The children tell the parent that they are quite successful, happy, and fulfilled, when in fact they are miserable, lonely, and depressed. They lie about jobs, friends, and experiences that do not exist because they know about the parent's interest in their happiness. Dworkin would call this unacceptable paternalism because the parent is made to believe her critical interests have been fulfilled when in fact they have not, and I would agree with him. The parent's critical interests will not be fulfilled, and she does not have the ability to become aware of that. Dworkin might say this example is analogous to the unacceptable paternalism in the case of Margo, because in both cases someone is stopping the person's critical interests from being fulfilled, and the person is unable to become aware of it.

I would respond to such an objection by saying that it is not the person's ability to know whether their critical interests have been fulfilled that matters, nor is it their ability to affect the fulfillment that morally distinguishes acceptable paternalism from unacceptable paternalism. Rather, it is the person's ability (or future ability) to know that she even has critical interests that distinguishes Margo from the misinformed parent. The parent desires her critical interests to be fulfilled (and not simply to believe they have been), while Margo is completely unaware that she even has or ever had critical interests. It is not wrong to ignore critical interests that a person will never have a way of knowing exist.

While Dresser makes many objections, both practical and theoretical, to Ronald Dworkin's theory of precedent autonomy surrounding advance directives and dementia, her theoretical objections would not worry Dworkin given the differences in basic assumptions between the two philosophers. I would object to Dworkin by questioning whether the paternalism present in making decisions for a patient with dementia based solely on her present condition is morally unacceptable. It is, I think, more analogous to cases in which paternalism is acceptable than it is to cases

in which it is unacceptable. Given this acceptability, I would recommend healthcare workers and families make decisions for dementia patients with the goal of bettering their current condition, rather than honoring their former wishes.

Bernstein and Weiner (1996, p. 268-269) admit that sometimes some studies seeking to explore the pathogenesis and clinical outcomes of a disease offer no therapeutic benefit to the research subject. Known as phase 1 studies, they administer medication to the subject in small doses, gradually increasing the dosage to test for the toxicity of the drug. In such cases, there is a potential for a tremendous amount of benefit on many levels. If a new drug is developed as a result of research, the researchers and institution gain recognition, while the drug companies amass profit. The research subject, however, gains no immediate benefit from his or her participation, save the fulfillment of altruistic motives.

Such a phenomenon whereby the benefit of research unduly favors the interests of the researchers rather than the subjects may be considered a “conspiracy of silence.” If the proxy decision makers or the subjects themselves

were consistently informed that phase 1 studies offer no therapeutic benefits, one would presume that enrollment in such studies would sharply decline.

Ostensibly, the issue of clinical research on cognitively impaired older adults is controversial. Kapp (2002) concludes that excluding older adults with mental impairments from the participant pool would unfairly limit research, a process that is necessary for clinical medicine to advance. However, Kapp also acknowledges the value of protecting the rights of those who are unable to protect themselves. 🙏

References

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