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POLEMICAL NOTE: CAN IT BE UNETHICAL TO PROVIDE NUTRITION AND HYDRATION TO PATIENTS WITH ADVANCED DEMENTIA?

– Rachel Haliburton –

Abstract. Patients suffering from advanced dementia present ethicists and caregivers with a difficult issue: we do not know how they feel or how they want to be treated, and they have no way of telling us. We do not know, therefore, whether we ought to prolong their lives by providing them with nutrition and hydration, or whether we should not provide them with food and water and let them die. Since providing food and water to patients is considered to be basic care that is morally required, it is usually only the provision of nutrition and hydration by artificial means that is considered to require ethical justification. Building on what I call a virtue-based conception of autonomy, I argue that, at least for some patients suffering from advanced dementia, even providing food and liquid by hand is morally wrong.

Keywords: advanced directives; artificial nutrition and hydration; autonomy; end of life; ethics; hand-feeding; virtue ethics.

The authors of “Ethical Issues Related To End Of Life Treatment In Patients With Advanced Dementia – The Case of Artificial Nutrition and Hydration” address an important and puzzling question: how should we medically treat patients with advanced dementia who are no longer able to express their own wishes? Marcus, Golan, and Goodman rightfully draw attention to an epistemic gap that makes this question difficult to answer: we simply do not know what is going on in these patients’ minds – whether they are happy or sad, frightened or content, whether they want to live or to die. Moreover, Marcus, Golan, and Goodman correctly warn us that we need to be careful not to let our own feelings about dementia colour our ethical and medical approaches: since dementia is something most of us fear developing, dementia patients tend to make us very uncomfortable, and we must guard against assuming that their lives have no value, for them or for us. The authors conclude that life-sustaining treatment should generally be provided to patients with advanced dementia, and that treatment decisions (including the provision of artificial nutrition and hydration) should be made on a case-by-case basis. However, the authors do not, in my judgment, clearly provide a set of con-

ditions or specify criteria that would allow caregivers to determine that this particular dementia patient should be fed while that particular patient should not be, beyond saying that we should perhaps not treat those whose “pain and suffering ... cannot be alleviated,”¹ and that any suffering entailed by the treatment needs to be carefully considered. However, the authors also state that “in the case of patients with advanced dementia, there is no indication that being in this state as such involves suffering,”² which suggests that the fact that an individual is suffering from advanced dementia should not in itself be understood as an ethically (or medically) justified reason not to provide treatment.

Further, given that the authors make extensive use of the principle of solidarity, which “entails a moral obligation to give severely demented patients optimal medical and nursing care, using the same medical judgment and considerations that any other patient would receive,”³ it seems clear that, in the authors’ view, it is not the provision of nutrition and hydration that will need to be ethically defended, but the decision not to provide it, since providing food and water is considered basic care for almost every patient. In short, the authors’ argument seems to be largely a defense of providing nutrition and hydration (by artificial means, when necessary) to patients with advanced dementia (which is to say, a defense of what is largely the *status quo* in many parts of the world), rather than a careful consideration of the grounds upon which we might conclude that, at least for some patients (and perhaps for many?) this treatment is not in their best interest, and how we might ethically make that case. While Marcus, Golan, and Goodman usefully identify the significant epistemic gap that confronts ethicists when faced with this patient population, I think that they do not take the implications of that gap – both for our ethical thinking and for our practical decision-making – seriously enough. This gap, I think, means not only that the provision of artificial nutrition and hydration would be morally wrong for at least some dementia patients, but so would hand feeding them when they are no longer able to feed themselves. (The provision of the former, of course, is usually seen to require more ethical justification than the provision of the latter).

I will make this case by briefly considering a tragic Canadian story, then explore the reasons why this epistemic gap means that our ethical theories and tools are able to provide us with very little guidance (a point that is also made by the authors, but which I want to explore slightly differently), and, finally, present

¹ Marcus, Golan, Goodman [2016] p. 126.

² Ibidem.

³ Ibidem, p. 125.

what I will call a virtue-based conception of autonomy that I think might provide us with ethical guidance, at least in the case of some patients.

In 2014, the Supreme Court of British Columbia determined that a nursing home should continue hand feeding Margot Bentley, an Alzheimer's patient at an advanced stage of the disease, over the objections of her family. The judge ruled that, because Ms. Bentley opens her mouth when food is offered, she is "providing consent through her behaviour when she accepts nourishment and liquids,"⁴ despite her doctor's claim that this action is only a reflex. Her daughter, Katherine Hammond, believes strongly that the decision was wrong based both on her current condition ("She's what I would [call] semi-conscious and vegetative; lying with her eyes closed most of the time, not moving, not speaking, diapered, lifted in and out of bed with a hoist"),⁵ and on her prior expressed wishes: Ms. Bentley, a nurse who worked on a dementia ward, wrote clear instructions that, should she develop a condition from which there was no hope of recovery and should she be rendered unable to express her wishes any longer, she did not want to be provided with "nourishment or liquids."⁶

Given the argument Marcus, Golan, and Goodman present, they would probably conclude that, not only was the judge's decision correct, but also that, when Ms. Bentley is no longer able to eat by mouth, she should be provided with artificial nutrition and hydration. I want to make the opposite case, and say, along with Ms. Bentley's family, that it was ethically wrong to continue with hand feeding, and that it would be ethically wrong, as well, to provide artificial nutrition and hydration to Ms. Bentley, and to other patients like her, those who have clearly expressed their wishes prior to developing dementia.

I want to begin by quickly rehearsing the reasons why the epistemic gap identified by Marcus, Golan, and Goodman provides us with a profound ethical problem, a problem that is exacerbated by our own fear of the disease. Since we do not know how those with advanced dementia feel, we do not know what they actually want, nor even what is in their best interests: does the fact that, when we are healthy, many of us feel that developing dementia would be our worst nightmare mean that it is equally intolerable for those currently suffering from it? Or is their experience so different from anything we can imagine, that we can genuinely make no judgement about whether their lives are good or bad, tolerable or intolerable, for them? Does the demented Ms. Bentley feel the same way about the disease

⁴ Hopper [2014].

⁵ Ibidem.

⁶ Ibidem.

that the healthy one did? Like dying, the experience of advanced dementia is a mystery, since only those who have experienced it know what it is like, but they are no longer able to convey their experience to us.

When it comes to providing us with guidance for how such patients should be treated, our ethical theories either “wield a sharp sword” and give us advice that is emotionally difficult to follow, or they have little to tell us. If we consider the most important ethical theories available to us to be utilitarianism, Kantianism, and virtue ethics, on certain plausible interpretations, each suggests, for different reasons, that we have no moral obligation to provide medical care (including nutrition and hydration) to individuals with advanced dementia.

Utilitarianism, arguably, tells us that providing treatment to these patients is a waste of resources (not just medical ones, of course, but also human and institutional): if we are concerned with doing what will produce the greatest amount of good for the greatest number of people, we need to think carefully about how we use scarce medical resources. It is hard to make the case, on straightforward utilitarian grounds, that the resources expended on caring for patients with advanced dementia would not be better spent on preventive health care for children, or on medical research. Moreover, the utilitarian would arguably take very seriously the fact that most of us fear developing dementia as significant: if we think that it is a disease that causes most people more pain than pleasure, we have few grounds to assume that the lives of advanced dementia patients are good for them.

Kantianism, despite its central focus on human dignity, does not offer us an easy way out, but may, indeed, be an even harder taskmaster. Since, for the Kantian, our worth and dignity resides in our capacity to act as rational creatures ought to act – namely, in our capacity to be able to recognize the moral law, and to follow it for its own sake, because we acknowledge that it is our duty to do so – it is quite easy to argue, on Kantian grounds, that the severely demented individual no longer meets the requirements of moral personhood – and, therefore, while still a biological human being, is no longer a “person” in the morally relevant sense. While this does not necessarily mean that such individuals should not be provided with nutrition and hydration, it does not clearly tell us that they should be fed and watered, either.

The situation for virtue ethics is very similar. Since, for Aristotle, we determine what we ought to do by tying ethics to teleology – by, that is to say, identifying what is best for us as individuals by identifying what is appropriate for members of our species – what it is to be a human being and what it is to be a moral agent are intimately and inextricably connected. Moreover, “human being” for Aristotle is not merely a biological concept, it is a functional concept as well. We

are, that is to say, human beings by virtue of our capacity to perform the functions typical of members of our species, and the most important of these functions is to act in accordance with the dictates of rationality. As the “rational animal,” we are poor, good, or excellent human beings when we fulfill our function badly, well, or with excellence; however, if we do not have the capacity to act as rational creatures ought, it is no longer clear that we should be considered human at all. It follows from this that the severely demented, who can no longer function as human beings typically do (and who, unlike infants and small children, have no hope of becoming rational creatures), are, in some sense, no longer human. Again, while this does not necessarily tell us that those with advanced dementia should not be given nutrition and hydration when they can no longer feed themselves, it does not tell us that they should be, either.

These results are unsettling, even disturbing: surely, most of us want to respond, something has gone badly wrong with our moral frameworks if they lead us to conclude that we have no real obligation to take care of some of the most vulnerable members of our community. However, what they point to, I believe, is not that our standard ethical theories, applied to these patients, lead us to results that most of us would find hard to ethically justify; rather, they point to the fact that the epistemic gap we are faced with when we consider how those with severe dementia ought to be treated is profound and difficult. These patients force us to ask questions – and, indeed, questions that are arguably as metaphysical as they are epistemological and ethical – that our theories did not envisage and are ill-equipped to address.

The virtue ethicist does, I believe, have one more move in her ethical argument, a move that is not as clearly available for anyone working within a Kantian or utilitarian framework, namely, to ask, not whether these patients are persons in the morally relevant sense, but, rather, how the virtuous physician, nurse, personal support worker, or other health care provider working with such patients ought to treat them. I will return to this question below, after first considering whether the ethical principles typically used in bioethics can offer health care providers clear guidance when working with this patient population, thus allowing us to bypass these theories altogether.

The four principles used most widely in North American bioethics (and increasingly incorporated in some form into bioethics internationally) are autonomy, justice, beneficence, and non-maleficence. Autonomy tells us that health care providers ought to respect the decisions competent patients make about their own health care, and that, when patients are incompetent, others should treat them either as they indicated they wished to be treated while they were still competent,

or that we should do what is in their best interests, according to some standard of what a rational person in their situation would choose.

As the case of Ms. Bentley makes clear, however, there seems to be a reluctance on the part of health care providers and the courts (and, almost certainly, many members of the general public as well) to view nutrition and hydration as medical treatment rather than basic care – even when it is provided artificially, and even more so when it simply involves hand-feeding. Moreover, given the epistemic gap – given that we genuinely do not know what these patients want, or even what is in their best interest (to live? To die?), the authors are correct to note that appeal to something like the objective or reasonable patient standard offers us little help. The most central question, however, in the case of patients like Ms. Bentley, I believe, is whether we can feel confident asserting that the healthy woman could predict how the sick patient would want to be treated; and how we answer this question will depend, as we shall see below, on how we understand autonomy.

For the same reason that we cannot apply an objective patient standard to determine how patients with advanced dementia should be treated, both beneficence and non-maleficence will offer little guidance. Beneficence, which tells us that we ought to do what is in the best interests of the patient, and non-maleficence, which tells us that we ought not to do things that will harm the patient, are equally unhelpful: we do not know whether prolonging their lives by providing them with nutrition and hydration is helping them, or whether letting them die would be harming them.

Finally, justice, which, in its most simple form, tells us that like cases ought to be treated alike, could, depending on how we interpret it, send us in two completely different directions. First, we might assert that patients with advanced dementia ought to be treated in the same way as all other patients. Since patients are normally provided with food and water without question, so should patients with advanced dementia. On this reading of the principle, we would be emphasizing what dementia patients have in common with all other patients, namely, that they are vulnerable persons who need our care. Conversely, we might emphasize the distinctness of this particular class of patients, and argue that, as a general rule, members of this group, once they reach a certain stage in their illness, should not normally be provided with nutrition and hydration, artificially or otherwise.

So, given that these principles also offer little help, how should a virtuous health care provider respond when faced with a patient like Ms. Bentley? I think, at least in the case of patients like her, those who made their wishes clearly known before they became ill and were unable to express them, that these wishes should

be respected. Moreover, I want to make this case by adapting the principle of autonomy so that it fits with what I will call a virtue-based conception of the self. Autonomy, which is usually understood (in bioethics and elsewhere) as consisting primarily in the capacity to make choices in light of our current conception of the good (a conception which remains revisable), and to take responsibility for the consequences of those choices, generates a conception of selfhood that is episodic. The choices I make today (for example, after I have embraced an aggressive form of atheism after losing my strong religious faith) will be very different from the choices I used to make (when my faith was very important to me), and I, too, become in some sense a different person, a new person, as my conceptions of the good change. Autonomy, understood as lying in the capacity to make choices, and selfhood, understood as residing in a series of episodes that are affected by the choices we make at different stages of our lives, is at a loss when we come to the epistemic gap generated by advanced dementia: we genuinely do not know who these patients are, whether they are, in some real sense, new persons who may have little in common with their previous selves, or whether they are the same people they used to be, to whom we can impute continuing desires, goals, and values.

But autonomy is a complex concept, one that can generate a number of related, but distinct, conceptions. A virtue ethicist would arguably not understand selfhood as being episodic, but would see it, rather, as consisting in a kind of ongoing story, one in which the choices we make form the shape of our lives which are themselves understood as having an essential unity, and which, when we are no longer able to express our wishes, others – particularly those who knew us best – have an obligation to tell our story for us, in a way that is congruent with the earlier chapters.

As well-known bioethicist Carl Elliot notes, we can understand the self in two radically different ways, and this will affect how we respond to someone like Ms. Bentley. If we ask the question, “Is she the same person she was when she was competent, when she expressed her clear wishes not to be fed or given liquids if she developed dementia?” we might answer, first, that no, she is not: because of the particular nature of her disease, the old self has disappeared and a new one has taken her place. As Elliot puts it,

One may well say... [that a severely demented patient], given her condition, could not be called to account for her past actions. She has changed irreversibly; she may

well not remember many of her actions; and when she carried them out, her personality and mental functions were radically different from her present ones.”⁷

On this reading, those taking care of Ms. Bentley should continue to hand feed her, because, in some very real sense, she is no longer the person who made the advance directive. Instead, that person no longer exists (except, of course, in the most basic biological sense), and the present person, for all we know – that epistemic gap again! – may have very different desires.

Second, we could argue, instead (and this is how, I believe, we should argue) that she is still the same person, that her life story only makes sense when we understand it as embodying a consistent narrative that unfolds over time. In this understanding of the self, who we are does not consist in discrete moments, but “is caught up with things that have happened in the past.”⁸ Moreover, if we understand our lives – and our autonomy – as consisting in a kind of unfolding story, one which links who we are when we were ten to who we are today, and who we are today to the person we will become in the future (a future in which we, too, might find ourselves suffering from advanced dementia), we can see that our stories link up with the stories of the other people in our lives (and vice-versa): our parents, our children, our spouses, our friends, our colleagues. When we are no longer able to tell our own stories, these other people have an obligation to tell our stories for us, and to tell them in such a way that the current chapters are consistent with what went before. Just as the Harry Potter story would not have been consistent if Harry had decided to join forces with Voldemort in the seventh book, so, too, a story in which Ms. Bentley would have been happy to be given nutrition and hydration when she reached an advanced stage of dementia is not consistent with her past life and the clearly stated wishes that emerged out of those experiences. (Notice that to make this claim is not to simply state that advanced directives should be respected; advance directives, in and of themselves, are often poor guides for determining how those who are unable to express their wishes should be treated, because they can be too specific – so that, for instance, they seem to rule out even temporary placement on a respirator; too general – so that it is not clear how they should be applied in particular cases; or not up-to-date with current medical possibilities. If advanced directives were adequate to do the job they are intended to, we would not have to worry about the epistemic gap, nor would there be any question about how Ms. Bentley should be treated. But they are unable

⁷ Elliot [1999] p. 135.

⁸ Ibidem.

to resolve all our treatment questions, and, I believe, thinking in terms of an unfolding story allows us to better respect not only the letter of what is spelled out in an advance directive, but the spirit in which those instructions were issued.)

I call this understanding of autonomy – of a conception of autonomy that develops and is exercised over the course of a lifetime and held together by a narrative thread, for as long as we are capable, and which can be picked up by others if we lose our capacity to express our own wishes – a virtue-based conception. Just as we can only understand virtues as dispositions that can be developed, acted upon, and perfected over the course of a lifetime, so that they become part of who we are, if we conceive of the events that compose any given life as being linked together in some unified way, so, too, the concept of autonomy only makes sense if we understand it as something more than the capacity to make choices. In addition, we must see it as a capacity that develops over time, is reflective of our ultimate goal to live the best life we can, is expressed through our actions, and as something which forms our character and influences the overall shape of our lives. A virtuous health care provider, consequently, when faced with a patient like Ms. Bentley, who both suffers from advanced dementia but who made her wishes clear prior to becoming ill, would respect those wishes, even if it means not feeding or hydrating her and letting her die. In light of her autonomously-expressed desire, moreover, feeding and hydrating her against her will is not only not morally required, it is morally wrong, both abusive and disrespectful. As Marcus, Golan, and Goodman correctly observe, dementia patients make the rest of us uncomfortable, since they are living manifestations of what many of us most fear; however, what makes dementia so frightening is not only the disease itself, it is also the fear that, if we develop it, our lives will be prolonged past the point at which they have value for us. This is a valid fear, and one that bioethicists and health care providers alike should take seriously.

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