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POLEMICAL NOTE ON MARCUS, GOLAN, AND GOODMAN, ETHICAL ISSUES RELATED TO END OF LIFE TREATMENT IN PATIENTS WITH ADVANCED DEMENTIA - THE CASE OF ARTIFICIAL NUTRITION AND HYDRATION

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Abstract. This polemical note looks at the ethical issue of providing artificial nutrition and hydration (ANH) to patients with advanced dementia from the perspective of an Aristotelian and naturalist ethics. I argue that this issue may be considered in terms of the Aristotelian notion of <u>eudaimonia</u>, well-being. I present a number of facts about the conditions of human life that contribute to <u>eudaimonia</u>. In addition, I present a number of facts about advanced dementia as well as clarify the goals of medicine. From these facts, I argue that we are not ethically obligated to provide ANH to this class of patients.

Keywords: advanced dementia, artificial nutrition and hydration, tube feeding, Aristotelian, naturalist, <u>eudaimonia</u>, arc of life, dignity.

Esther-Lee Marcus, Ofra Golan, and David Goodman, in their article *Ethical Issues Related to End of Life Treatment in Patients with Advanced Dementia – The Case of Artificial Nutrition and Hydration*, seek to shed some light on the moral obligation caregivers have towards patients suffering from dementia or advanced dementia. They explicitly state that the related question of resource allocation is beyond the scope of the paper, limiting the scope to the ethical issue of whether life-sustaining treatment in the form of providing artificial nutrition and hydration (ANH), or tube feeding, is morally required for this class of patients. A number of moral principles, rights, and values are considered along with an assessment of their usefulness or applicability to this group of patients. There is also some discussion about the empirical facts that ought to be considered in any ethical deliberation on the provision of ANH to (severely) demented patients.

As a general remark, I find the authors' treatment of many of the moral principles, rights, or values too hasty. For a short paper of 15 pages, there are far too many of them presented for our consideration. As far as I can see, the authors suggest that a decision to provide ANH (or not) to patients with (advanced) dementia might be based on 1) the patient's prior expressed wishes; 2) the patient's best interests; 3) the presumption that a person wishes to continue living, unless

proven otherwise; 4) the ethical rule "when in doubt, favour life"; 5) the four prima facie moral principles of principlism in bioethics, namely, autonomy, beneficence, non-maleficence, and justice; the principle of justice is then interpreted either as (i) the (demented) patient's right to life, which is equal to the right to life of all other persons, or as (ii) serving the well-being of all patients equally (which may not necessarily include sustaining life by all means); later in the paper the scope of the right to life is claimed to include the right not to be killed unjustly, while the inclusion of the right to be kept alive is claimed to be less clear; 6) the moral values of care and human dignity (the dignity of the human person); 7) the principle of solidarity (a value of European bioethics said to be like the principle of equality found in American bioethics); 8) Cohen's concept of "best care" (said to encompass both the caregiver's solidarity with and the best interests of the patient); 9) Głos's concept of "relational personhood," which includes the basics of human relationships, love, and unity; 10) Pellegrino's three interpretations of the value of human life (i.e., absolute, relative, and instrumental); 11) a teleological approach by considering the goals of treatment, which for end-stage dementia are said to be to provide care and to show respect for the patient (thereby alleviating their suffering); and finally, 12) human dignity, the main concept behind the goal of showing respect for the patient; and this notion is understood in terms of (i) Kant's concept of dignity based on rationality, (ii) Oliver Sensen's reinterpretation of Kant's concept as a maxim of not exalting oneself above others regardless of their rationality, (iii) the dignity of being created in the image of God, and of having a human genome, (iv) Nordenfelt's four notions of human dignity, and (v) Menachem Elon's view that the life of a human being is itself the human dignity of man. In addition to the hastiness with which the authors are necessarily forced to treat each of these ethical guidelines individually, the transition from one to the next is often accompanied by insufficient reasons for rejecting one in favour of another.

Similar general comments could be made about their discussion of the relevant empirical facts to be considered in our moral deliberations on the matter under consideration. Though the authors correctly point out that "good ethics starts with good facts," they attempt to argue that in the case of people with (advanced) dementia we have very few, if any, objective facts about the subjective experiences of such patients. It is impossible for us to know whether they are suffering miserably or whether, instead, their souls have been released "to a hi-

¹ Marcus, Golan, Goodman [2016] p. 122.

gher spiritual level."² Likewise, we cannot clearly demonstrate empirically the benefit or burden of tube feeding these patients, that is, whether feeding alleviates suffering and sustains the life that remains for a longer period of time. The paradoxical result is that despite their recognition of the importance of having facts at the base of our moral deliberations, on this ethical issue we have, so it would seem, almost no empirical basis upon which we can build our ethical reasoning.

The weaknesses noted in these general remarks are apparent in the paper's conclusion. Regarding the ethical guide caregivers might follow, the authors propose the concept of the dignity of every human life and the value of solidarity. Unfortunately, they do not clearly specify which of the various, even incompatible, conceptions of human dignity is being employed. For instance, the Kantian concept based on rationality is not compatible with Sensen's concept which disregards rationality; and these are not compatible with Elon's concept which essentially equates dignity with life *tout court* and seems to express a vitalist conception. Moreover, the paper's conclusion includes the judgment that both withholding ANH and providing it can be ethically justifiable actions. This seemingly contradictory judgment is possible because the authors allow persons other than the demented patient to make their own empirical assessments regarding the efficacy of ANH to sustain or prolong life and/or to alleviate suffering: for those who believe that tube feeding does neither (or not one) of these, it would be ethical to withhold ANH; for those who believe the contrary and that withholding ANH would cause the death of the patient by starvation, it would be ethical to provide ANH. In other words, it is the substitute decision maker's, or perhaps, the caregiver's perception of the empirical facts that would justify, in part, the ethical decision to be made. The contrary empirical judgments and actions could both be seen to follow the concept of the dignity of every human life and the value of solidarity.

What is worth noting is how Marcus et alia attempt to shift the focus of the discussion from debates about the quality of life and personhood of patients with (advanced) dementia towards the topic of tube feeding and whether it is beneficial to such patients. It is clear that the authors find morally repugnant any arguments and claims that would see these patients as not having equal value as other human beings; unfortunately, they do not provide us with much moral guidance since they leave the benefits of tube feeding open to interpretation. Though there are a number of criticisms and objections that could be raised with respect to the specific points noted above, this polemical note will instead focus on the paper and its topic from a different and definite point of view. The perspective I would like to

² Ibidem, p. 123.

take is that of an Aristotelian virtue ethicist and a naturalist ethics.³ What exactly is meant by these labels will be made clear in the course of my critique.

I agree with Marcus et alia that good ethics starts with good facts; however, unlike them, I think there are more objective facts regarding patients with (advanced) dementia and the nature and effectiveness of ANH which are ascertainable through common experience and scientific methods. As an Aristotelian, one could state a number of facts about the human species, that is, properties or characteristics we all share by virtue of being the kind of biological organism that we are. The first fact is that human beings have a limited biological life span. Every individual person is born; and every one of us dies. Birth and death are the parameters that measure human life. Whether there is another form of life after this one on Earth, the human mind is incapable of knowing; but such a possibility could be accepted on faith. The same can be said about God or any divine being as source or cause of biological life and with whom human beings may or may not cultivate a relationship. An Aristotelian and naturalist is (or ought to be) agnostic on such matters.

A second fact is that there is much variety in the span of life for each individual human being. A normal life span, the natural one for humans, is to live long enough to be able to live through all of the main periods of life: childhood and adolescence, adulthood, and old age. We know that the number of years covered by a natural life span has some variation. According to the authors, old age is currently set at 74–84 years and old-old age is 85+ years. This might be the norm for those living in developed countries; those living in underdeveloped countries likely have shorter life spans. Whatever the number, the number of days on Earth allotted to each individual varies. And we all know people who have not lived the full span of life, and that is tragic.

Another fact of human life is that it has a definite direction: it starts at birth and ends at death. This temporal linearity is evident in the arc of life. Childhood and adolescence are periods of growth, adulthood is a period of flowering and maturation, and old age is a period of decline, decay, and degeneration. Once again, the particular details vary from person to person, but there is a general arc to our lives. The experiences we have within each of these periods, and how we experience things as we move through the stages changes throughout our lifetime. For instance, the kind of love experienced in each period of life, and how this constant phenomenon called love is differently experienced as we age are signs of the

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³ I have already presented an Aristotelian approach to end of life decision making in a previous issue of this journal. See Biondi, Haliburton [2015].

linear direction in the experience of human life. In other words, the temporal linearity is embedded in our genes—biologically and physiologically, in our psychology—experientially, and in our relationships—which can deepen with time.

Yet another fact of life is its fragility. We are all vulnerable to death, to illness, to events that drastically and unexpectedly change the course of our lives for the worse. Such unwelcome events can happen at any time of life. Cancer has taken the lives of children, sadly. But again, we can paint in general terms a natural course of life. Youth is usually a time of health and vigour, whereas old age is, generally speaking, a time of declining health and degeneration. As people live longer, this final period of life may still be one of relative health and activity for some; for others, however, it is a period of more or less slow decay, an inexorable progression from illness to illness, from dementia to advanced dementia. For some, the moment of death may come swiftly. For others, the moment of death may not come soon enough; there is a long period of dying before the moment comes. Aristotle makes a distinction between movement and change.⁴ Movement is a process that occurs over a period of time; change is something that occurs in an instant. Death is a change; but sometimes death is preceded by the process of dying, by the movement towards death. Thus, the movement towards death is sometimes a part of a person's life. For those of us who live to an old age, this period often includes the process of dying in several ways: our bodies lose certain of their abilities, our minds (brains) lose some of their capacities, and our relationships come to an end as we attend more funerals than baby showers or weddings. All of these are losses and naturally experienced as such, although words of encouragement from others, a cheerful and optimistic disposition, or faith in God and hope may help to lighten the load.

These facts based on our common experience of human life can help us to assess the initial sections of Marcus et alia's paper. They are correct in pointing out that people living with dementia and advanced dementia are for the most part elderly, and even quite elderly. They are correct in noting that they are frail and ill, and consequently require care and attention, even constant care. I think they are justified in claiming that demented people "remain equal members of the human community"⁵ or that they are persons (or have personhood). However, I think they are mistaken in urging us to fight against the commonly-held perception that the life of people with (advanced) dementia is not a life worth living or constitutes a lower quality of life. They are mistaken in warning us to guard against "the con-

⁴ Aristotle [1984] *Physics* III, 1-3 and V, 1-2.

⁵ Marcus, Golan, Goodman [2016] p. 120.

scious or unconscious preference of death over life for these patients."⁶ Contrary to their claim that our understanding of patients with advanced dementia "involves extreme views about the value of the patient's life and the misery of being in such a state,"⁷ it is perfectly reasonable to perceive such a state as something we wish to avoid. As the authors note, the elderly themselves perceive dementia "as the most frightening condition," more fearful than other serious illnesses of the body. Unless one is blessed with health, old age is burdensome; and if we add to the typical burdens of old age the added burdens of dementia, such burdens are reasonably feared by most people. This is not extreme; this is rational and reasonable.

The authors—along with many others involved in the debate about tube feeding patients with advanced dementia—confuse and conflate human dignity with quality of life. I contend that it is possible to look at human life from the point of view of the nature of the human species, and to judge that a certain kind of life is not compatible with a flourishing and fulfilling human life. I am referring to the Aristotelian notion of eudaimonia, well-being or flourishing: a human life of a roughly normal life span that allows one to experience all of the varieties of experience found in each period of life; a life that has enough of the requisite material conditions: material goods (like enough wealth to meet one's basic needs) and bodily goods (like health); a life in which one cultivates a moral character that enables one to form harmonious and satisfying relationships with others; a life that exercises our higher cognitive abilities (the goods of the 'rational soul', to use Aristotle's terminology).9 With this notion in mind, any illness can be said to diminish human well-being to some extent. Health is preferred to sickness because it makes human flourishing possible and is even a part of it. Because old age is normally accompanied by diminishing health, it can take something away from our experience of living a fulfilling life. When old age is accompanied by an illness such as dementia, which has the potential to develop into the more serious, irreversible, and (currently) incurable illness of advanced dementia, it is difficult to perceive it as anything other than an obstacle to <u>eudaimonia</u>. In most instances, the person is really living the movement towards death.

But this assessment of quality of life made in terms of a general conception of <u>eudaimonia</u> is not a judgement about the dignity of human beings in general or

⁶ Ibidem, p. 121.

⁷ Ibidem.

⁸ Ibidem, p. 119.

⁹ Aristotle [1984] *Nicomachean Ethics*. See, in particular, book I, 1–12.

that of any individual person. It is still logically possible to separate the individual as a person from the current state or condition of their life. In other words, the individual as a human being or as a person (I make no meaningful distinction between these two labels) can be claimed to possess dignity simply by virtue of being a human being or a person; but that same individual can still be claimed to have a poor quality of life, one not worth living, by virtue of being in a condition that makes the achievement of <u>eudaimonia</u> extremely difficult if not impossible. In somewhat Kantian terms, to say an individual possesses dignity is to perceive that individual from an a priori or abstract (or noumenal) point of view. To say an individual has achieved <u>eudaimonia</u> (or not) is to perceive that individual from an a posteriori or concrete (or phenomenal) point of view. Furthermore, what happens on the empirical plane can do nothing to diminish or take away from the dignity inherent in being human or a person. It is only the conflation and confusion of these two perspectives that makes it possible to think that a judgment about quality of life is necessarily a judgment about human dignity. Jesus' death on the cross may have been an 'undignified' way to die; but he never lost the divine dignity he possessed. And Socrates repeatedly claimed that his enemies could physically harm him, take away his property, banish him from Athens, and even kill him; and yet, he would still retain his human dignity.

For the sake of argument (and to respect the constraints of this note), I will merely state that any individual member of the human species possesses human dignity (moral worth)—the human species being the reference point for understanding <u>eudaimonia</u>, too. Intuitively, we justify according dignity to human beings simply by virtue of the fact that they are human beings. There is no need to try to confer dignity upon them by virtue of some other property they must possess (be it rationality or life, or whatever). Thus, persons suffering from (advanced) dementia possess human dignity. But what is the kind of care that would respect their dignity and that caregivers are morally obligated to provide to them?

To know how to treat persons with (advanced) dementia with dignity, we need to clarify the empirical facts of this pathological condition. Dementia is a disease of the brain, a neurodegenerative disease. As a consequence, it affects our minds, which is so important to the maintenance of memory and thinking and speaking and self-identity and relationships with others. It is legitimate to fear this disease because it does attack the physiological basis of our core psychological and social selves. Furthermore, it is a disease for which there is currently no cure, and to make matters worse, it is progressive. Thus, it is irreversible and incurable. As dementia progresses to advanced dementia, sufferers manifest other symptoms by becoming incapable of carrying out basic activities of daily living, performing

basic bodily functions, and yes, having trouble eating and swallowing. In short, dementia is not simply a disease that affects memory and higher cognitive functions. It is a disease that affects many non-vital and vital functions controlled by the brain. There is, therefore, a constellation of symptoms associated with the condition, and the list of symptoms grows as the disease progressively worsens. More importantly to the matter at hand, the inability to eat and swallow is a symptom of advanced dementia. From my understanding of it (I admit I have a very limited medical background), this symptom occurs in the final stage of the progression of the disease.

Consequently, when the authors assert that "there is no indication that being in this state as such involves suffering,"10 are they including the symptom of the lost capacity to eat? Or are they, as I suspect, excluding that symptom and only focusing on those related to the higher cognitive functions? Besides, given their claim about the difficulty for others to know of their subjective experiences, how can they be so sure that patients with advanced dementia experience no (or little) suffering? Furthermore, when they speculate about the subjective experiences of patients with advanced dementia, they suggest it may be possible for them to still have spiritual experiences. Although I agree with their claim that it is very difficult for us to know what their subjective experiences are—the same can be said to some degree about any other person I meet, this possibility does seem implausible. The brain is the physiological condition for any sort of experience. Since dementia is a disease of this crucial organ, and since we see the loss of so many other abilities that require the healthy functioning of this organ, it does seem initially implausible for this capacity to remain without being adversely affected in some way. Whatever the truth of the matter is, a scientific understanding of the functioning of the brain can provide some guidance as to what mental, cognitive, and physiological functions are lost as the brain progressively deteriorates. At this point in time, we are only near the start of gaining such an understanding of the brain, so definitive claims will have to wait. However, the preponderance of current evidence makes it reasonable to believe that patients with advanced dementia have an ever diminishing horizon of subjective experience.

Imagine the following scenario: Two brothers in their late teens are involved in a minor car accident. One escapes unharmed; the other ends up with two broken wrists and some damage to his hands. Lacking the ability to use his hands, the invalid brother is now dependent on his healthy brother for the performance of many basic activities such as going to the washroom, bathing,

¹⁰ Marcus, Golan, Goodman [2016] p. 126.

dressing himself, and eating. At meal time, the healthy brother feeds the injured one by putting the food into his mouth with the usual utensils and sometimes even by hand (such as, for grapes, which the injured brother relishes). The injured one has no problems chewing and swallowing his food. Eventually his injuries heal and he resumes living his life as before (perhaps with a few limitations).

Now imagine this scenario: There are two elderly patients with advanced dementia. One lives in contemporary Europe in a country that has all of the latest medical technologies and medicines. The other lives in an underdeveloped country with none of these technologies and medicines – much as was the case for our European ancestors before the invention of such medical wonders. As the dementia of the patient living in the poor country worsens and progresses to ever more advanced stages, the number and severity of symptoms increase. The person eventually loses the capacity to eat and swallow on her own. She eventually dies. It is quite likely that her death will be attributed to the disease that progressively took her capacities away. It is possible that a few others will say she withered away because she was no longer able to eat. They may even claim that she starved to death. But, I believe, the cause of her death would not be attributed to starvation alone, if at all. It would be attributed to the pathological condition that took this and the other capacities from her. The patient in Europe, in the meantime, is in the same pathological condition we are considering. She may or may not be inserted with feeding tubes. As Marcus et alia argue, what is done with her will depend on how the substitute decision maker or caregivers view the empirical fact of tube feeding and the potential cause of her death. They decide to insert the feeding tube because they believe she would starve to death without it. This means the patient would have to be placed in a hospital or similar medical setting. It would require medical personnel trained in inserting the tube and knowledgeable in preparing the nutrients. It might even require other interventions if complications such as infection were to arise. Even with the feeding tube, the patient will eventually die from the incurable disease of advanced dementia. If we accept the authors' views, we do not know (currently) whether the feeding tube actually sustained the life of the patient longer and reduced her suffering more than without its use.

Both of these scenarios are intended to paint a naturalist picture of the condition of patients suffering from advanced dementia for the purposes of comparison with our current technological medical culture. What would people do in a time and place where the technologies of tube feeding are not available, if human beings were left to their own natural devices? The first scenario is intended to show what feeding would be like when it is considered basic care. The healthy

brother is able to prepare the meal at home and feed it to the injured brother. No medical knowledge and training is required on his part to accomplish these tasks. The injured brother is able to eat all on his own. No feeding tube is required to accomplish this task. The injury is curable, and the injured brother is healthy enough to resume living once the injuries heal.

The second scenario is intended to show what the cause of death would be, or rather, how it would be perceived and attributed to the patient that dies after suffering from advanced dementia. For the patient in the underdeveloped country it is quite probable that the death would be seen as caused by the pathological condition, which includes the inability to eat. The death would probably be said to be by "natural causes." For the patient in the developed country, the cause of death would be attributed to the dementia with the inability to eat excluded from the disease. Furthermore, this scenario when compared to the first one shows the difference between basic care and medical treatment or care. Empirically, tube feeding is a form of medical treatment; it cannot be categorized as basic care.¹¹

Basic care is something provided to people who are relatively healthy and contributes to the maintenance of their healthy state. Medical treatment, on the contrary, is provided to those in a condition of illness, when their health has been compromised in some way. The one brother is injured, not sick. His brother is providing basic care. The patients with advanced dementia are ill, suffering from a pathological condition. When a treatment is able to restore a sick patient to a state of health, then that is properly construed as medical treatment. But when a treatment is unable to restore the state of health, then we are really dealing with management, and not treatment properly speaking. Moreover, if the illness is such that it will progress towards the death of the patient and there is no treatment to stop this movement, then we can provide comfort care or palliative care.

In other words, since the Aristotelian approach incorporates a teleological approach to human life and activities, we can employ it to gain a more accurate understanding of the goals of medicine. I think that the distinctions just made help to clarify the different goals of medicine, which vary according to the condition of illness and our current abilities to restore the condition of health and stave off death resulting from a given pathological condition. Ultimately, the goals of medicine are subordinate to the overarching goal of achieving the <u>eudaimonia</u>, the well-being, of the individual as much as possible. Medical decisions should be made with this ultimate goal in mind.¹²

¹¹ Clary [2010].

¹² Cf. Collier, Haliburton [2015] p. 317-318.

Let us now tie the various strands of thought together. Elderly patients with advanced dementia are, as Marcus et alia say, people living "in a twilight zone between life and death."13 But given the linear direction inherent in the arc of human life, it is more accurate to say that they are in the final period of life and in the process of dying, and thus, they are living in the twilight of their lives and the dawning of their death. As their dementia advances, they lose more and more of their capacities. Eventually, they lose the capacity to eat and swallow. This is a symptom of the pathological condition. Empirically speaking, it is incorrect to consider this inability apart from the other capacities lost by virtue of the dementia. Empirically speaking, it is incorrect to construe tube feeding as basic care. It is a medical intervention that can only be administered by those with medical knowledge and training; and it is a medical intervention administered only to those who are injured or ill. Empirically speaking, when the person dies, the cause of death is the advanced dementia, not starvation; or perhaps, starvation may be considered a direct cause only because it is a symptom of the indirect cause which is the advanced dementia. If there were no dementia, there would be no problem with eating (assuming no other cause of this problem).

Starvation implies the person is still hungry. Anybody who has experienced being very ill (which is likely every one of us) knows by experience that, generally speaking, we lose our appetite when we are in that condition. Though I lack the scientific knowledge of how our bodies are affected when starved (and dehydrated), it seems reasonable to think that we do not feel hungry when we are ill because digestion requires energy resources, resources our bodies cannot (afford to) expend when they are compromised by a serious illness. Even healthy old age reduces our appetite. We eat less during that period of life than in adolescence and adulthood. Elderly people with advanced dementia are likely not very hungry to begin with. Marcus et alia state, "[n]early 90% of persons with advanced dementia develop eating problems, which may cause malnutrition." Perhaps it is not so much malnutrition as it is degeneration. In other words, the depletion of nutrients is likely another symptom of a body that is shutting down and in the process of dying.

As a consequence of these empirically (and relatively) ascertainable facts, it does not seem reasonable to continue nourishing a dying body for fear of starving it to death. Let me be clear. I am in no way suggesting that we dispose of the elderly living with (advanced) dementia. The respect owed to beings possessing dignity

¹³ Marcus, Golan, Goodman [2016] p. 126.

¹⁴ Ibidem, p. 128.

forbids killing them, as the authors suggest in their paper. However, from an Aristotelian and naturalist perspective, it does not make much sense to insist that such persons must be nourished by artificial means when they have lost the ability to eat as a symptom of a pathological condition for which we have no cure. Such persons are in the process of dying and nearing the end of the arc of their lives. That is the reality before us, which is why so many of us have a difficult time facing and accepting it.

But that does not mean we kill them or abandon them. We provide them with comfort or palliative care, and this care does not include ANH. It includes cleaning them and bathing them and feeding them via the mouth, naturally, to the extent that this is possible, and hydrating them, even if only by sponge and moistening their lips to lessen the discomfort of feeling thirsty. The care should even include some of the values examined by the authors such as the principle of solidarity, Cohen's concept of "best care," and Głos's concept of "relational personhood." Even though I doubt that persons with advanced dementia are capable of reciprocating these things, I believe that we still ought to maintain the basics of human relationships, love, and unity with them just in case they are still capable of receiving our care and concern for them without being capable of expressing it in return. It is said that hearing is the last of the senses to go, so let us not go silent by withholding soft words of comfort to them until their death.

On another note, I cannot avoid raising the issue of resource allocation. The authors acknowledge that this is a "related question," but also that it is beyond the scope of the paper. The constraints of space imposed by the form of the academic paper make this a reasonable limiting of the scope. However, I do think that the final word on the ethical obligation caregivers have towards patients with (advanced) dementia cannot be said without considering the macro obligations of the healthcare system within the broader context of the socio-political community as a whole. This concern follows from the Aristotelian view of human beings as political animals (a point acknowledged by Glos in the concept of "relational personhood").15 As members of a society, our ethical deliberations must include the broader arena of justice in the allocation of resources. Thus, any discussion of our ethical obligations towards patients with advanced dementia and whether they should be given ANH cannot help but see this as a 'bourgeois' concern, a concern of literally a handful of people living in the developed world. The majority of people on the planet live in underdeveloped parts of the world. Many of them are still young enough and/or healthy enough to require food, yet they are malno-

¹⁵ Aristotle [1984] *Politics* I, 1–2.

urished and experiencing the pangs of hunger. They do suffer from hunger, starvation, and the anxiety that comes from insecurity in procuring food on a daily basis. These are ascertainable facts, too. These billions of people, who are living in conditions of greater or lesser poverty, which pose many obstacles to the achievement of their <u>eudaimonia</u>, ought to be kept in mind as we deliberate about extending for a relatively brief period the lives of a relatively few people caught in the inexorable process of dying at the end of a full span of life.

As may be gathered from this polemical note, I readily admit that I do not hold the same position as the authors. I detect a "pro-life" stance in their paper. It is evident in their reference to the notion of a right to life, which is incorporated into the principle of justice. It is evident in a couple of the conceptions of respect for dignity, for example, in Elon's apparently vitalist view which equates dignity with life. It is evident in the moral position of the presumption that a person wishes to continue living, unless proven otherwise and in the ethical rule "when in doubt, favour life." It is also evident in the inclusion of respect for the patient as a goal for care, which then makes it possible for the authors to incorporate the various conceptions of dignity within the goals for care. It is also evident in their use of the expression "life-sustaining treatment." I find such attempts to substantiate a right to life misguided and problematic mainly because where there is a right, it imposes a correlative obligation on others in society to meet that right. Medicine cannot meet that right. In fact, medicine will often fail to meet it because there remain many illnesses and pathological conditions that defeat our medical knowhow. In short, I find the concept unhelpful and inappropriate for the reality with which we are dealing. It is a moral judgement that leads to a misperception of that reality.

Finally, this paper raises, for me, the intriguing question of the fact/value relationship. Those influenced by Hume make a neat divide between fact and value, between is and ought. As an Aristotelian, I do not share this view. I think that there is a closer relationship between the two; however, I admit that I am still not yet clear on the exact nature of that relationship. As a question of epistemology, I am aware of the difficulty in keeping our perception of empirical fact free of the influence of an evaluation in terms of value or of moral judgement. I have attempted in this note to present as many of the empirical facts regarding the provision of ANH to patients suffering from (advanced) dementia as free from value judgments as possible. I have attempted to present as objective a picture of the reality as I possibly could have. I have also noted those facts for which I lack scientific expertise but which I think can become known by scientific methods and careful observation of persons who decide to forgo (any) nutrition and hydration in the

final stage of a degenerative pathological condition. I have done so because I believe that a correct perception of empirical reality is a requisite condition of ethical deliberation and of coming to the most reasonable and moral course of action. After all, good ethics starts with good facts. Yet, I am left with a nagging doubt that I, too, may have been influenced by my own judgments about the (lack of) value of tube feeding such patients.

I end with this analogy: if Marcus et alia and I were presented with a glass half-filled with water, I suspect that they would say it is half full, while I would say it is half empty. Why?—By analogy with their perception of the elderly patient with advanced dementia as still being alive, my perception of that person is of an elderly person in the process of dying. Which is correct, that is, a more accurate picture of the empirical reality? I would say that my picture is more accurate because the water is being drained from the glass, and not being poured into it. But we will not perceive that fact unless we perceive empirical reality as would an Aristotelian naturalist who looks at human life holistically and in its dynamic unfolding through time.

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