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An Approach to Weighing the Benefits and Burdens of Artificial Hydration and Nutrition

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Through the debates over provision of artificial hydration and nutrition (AHN) during the last several years, an opinion has been emerging which favors assessing benefits and burdens to each specific patient deciding the reasonableness of such treatment in that case. Specifically, this approach has been recommended by the *Barber* case,¹ by the President's Commission,² and by the Sacred Congregation for the Doctrine of the Faith.³ This is an appropriate basic method, but because individuals define terms differently and assign varying weights to values, a whole range of different practical guidelines results. For example, some writers claim that food and fluid never can be denied,⁴ while others feel it is appropriate to withhold them from patients who are terminal^{5,6} or demented.⁷

The purpose of this essay is to explore the meanings of terms used and values weighed in the debate. An ethical framework to underlie decisions will be proposed; practical guidelines with which to apply that value system will also be offered. Thorough discussion of that which lies behind decision-making is essential in order to know what value commitments are represented by particular conclusions. Reliance solely on decisions of court cases will not always guide one to a course of action consistent with a coherent value system. It is all too common at the level of practice to avoid fundamental questions of value by substituting legal requirements for moral decision-making. Thus, while readily admitting the difficulty of weighing priorities and drawing lines of moral distinction, we must set out to do just that.

Definition of Terms

1. Treatment. One major source of disagreement derives from differing definitions of this term. The debate revolves around whether AHN should be considered medical treatment in the same manner as are respirators, antibiotics, and dialysis. The courts generally have ruled that it should be so considered, as seen in *Barber* and the final decision in *Conroy*. It is clear that controversy persists, since in the lower courts' responses to *Conroy* and *Brophy*, it was ruled that AHN was not equivalent to medical treatment. The distinction is important, because if AHN is considered to be part of "ordinary routine care", as a variation of a basic condition of life, then the obligation to provide that ordinary care is more stringent than to provide that which is considered a "treatment".

My view is that AHN is a form of treatment; however it is not equivalent to other forms of therapy. There exists a continuum of treatments of varying degrees of invasiveness and moral requiredness. Putting AHN in the same category with other treatments does not make them interchangeable. Certainly antibiotics, AHN and decubitus ulcer prevention are at one end of the spectrum and cardiac catheterizations and neurosurgery are at the other. They should not be lumped together so that a decision about one form of therapy is found automatically to apply to the others. This is not a reasonable approach, but it is used in many arguments.^{8,9} Rather, treatments should be seen as being on a scale of requiredness, and the degree to which it will be appropriate in any specific case depends both on the nature of the treatment itself and the circumstances of that particular patient. For example, since the nature of AHN is that it is generally noninvasive, basic and benign, much stronger mitigating circumstances would be required to justify its discontinuance. However in another patient, the process of providing nourishment in this way might be such that it is not benign, e.g., it could itself be causing repeated aspiration pneumonia, congestive heart failure, sepsis or constant physical restraints. On that basis it would be less required. Thus labeling AHN as a treatment should not lead one immediately to certain conclusions about its necessity as the courts have implied.

2. Dying. This is another term, the definition of which can vastly change the outcome of a decision. This definition can vary on at least two levels. First, it may be used to describe patients who, were it not for the present availability of technology capable of feeding them, would be dying. That is, this position holds that it is the underlying disease, through its creation of the patient's inability to eat, that is causing his/her death, and that AHN is prolonging it through intervention.¹⁰ Using this definition can alter decision outcomes, because some authors, including the AMA in its "Statement on Withholding or Withdrawing Life-Prolonging Medical Treatment", have held that AHN is not required for dying patients.¹¹ If this definition is used, then all such patients would be seen as "dying" and thus none would require the use of AHN. I find that, although this definition of

dying makes a point, it is not convincing enough on the argument's own merits to say that a certain treatment is not required, simply because patients died when it was unavailable 50 years ago. Thus we see that the definition of dying can be dependent upon the state of technology.

The second level upon which the definition of "dying" can vary is that of time reference. Very often, in the literature, "dying" or "imminently dying" is taken to mean that death is expected within a year.^{12,13,14} My sense is that this time frame is too long, and that something closer to one month would be more appropriate. The reason this is important is that once a person is classified as dying, there is a less stringent obligation to provide treatment. The longer the time frame given, the more people and the broader the contexts which are included in the implications of court decisions. Extending the term "dying" to include persons whose deaths are expected within a year can be misleading, because many people may have a diagnosis which has that prognosis, but at the present time are, in fact, in a robust general condition. In that sense, they are in a state no different from that of the rest of us, except that we are less able to predict our deaths. Thus, to discontinue providing AHN to them would seem inappropriate, and so I feel that the use of the term "dying" should involve some indication of physical debilitation rather than just a relatively better ability to predict the ultimate demise which will affect us all. Moving the time reference back to one month generally would accomplish that aim.

3. Effectiveness. Another term which requires more clarity in its use is the proposed "effectiveness" of a treatment or, conversely, its "futility." For example, it is often stated that if a treatment offers no possibility of improving a patient's condition, then it need not be utilized.¹⁵ On the surface, this statement makes good sense. Why do something which will not make any difference? However another level of understanding is reached if one further dissects the meaning of the word "effective". What is it that we want the treatment (e.g., AHN) to effect? Does it have to cure an underlying condition or does it have to maintain a person at his/her present level and leave the underlying disease untouched? Many authors imply the former. For example, Rebecca Dresser and Eugene Boisaubin state that "Nutritional support should be withdrawn only in the presence of the highest degree of medical certainty that the incompetent patient's condition *will not improve* to any noticeable extent" (emphasis added).¹⁶ If one looks to AHN to effectuate a cure or an improvement of a disease, it will nearly always fail to meet that standard and thus be deemed ineffective and unnecessary. I think that it is unreasonable to expect that AHN should serve as a cure or even provide significant amelioration of the disease state, since that is not its true function. It basically serves to support and maintain the patient's present physiologic condition with greater strength and nutritional reserve than otherwise would be possible. In that sense it does constitute an "improvement". This fact alone does not mandate its provision, but neither does the sole fact that AHN will not be effecting a

cure constitute sufficient reason to discontinue it. The entire context must be considered. For example, if a patient is permanently comatose, I may find that maintenance of the physiologic state is not of benefit, but in the case of an incompetent schizophrenic patient, such maintenance may be beneficial.

4. Burdensome. This broad, inclusive term takes on great importance in the benefits burdens analysis, but has multi-faceted connotations. Because of this ambiguity, discussions in this area should be explicit about the aspects of the "burden" to which reference is made. Is a burden emotional or financial? To whom is it a burden—the patient, the family, the caretakers, society? To whom do we owe our primary concern to spare discomfort? Is the patient uncomfortable or are we trying to relieve our own discomfort about staying with a patient in a hopeless or cognitively deficient state? If the patient does not feel pain, as in a coma, does our responsibility end there or does it extend to the grieving family or society? These questions are not easily answered, but it should be recognized that they are implicit in our use of the term "burdensome", and to reach a better understanding of our value systems, we should be more explicit in our use of the term.

5. Incompetent. This last term to be evaluated is meant to describe those patients who, because of cognitive deficits and/or psychiatric factors, are unable to appreciate the nature of their condition, the possibilities for treatment and the implications of decisions. This term applies to an incredibly varied spectrum of conditions and very different resultant mental and social capabilities. For example, all of the following classes may be deemed incompetent: healthy children, schizophrenics, comatose individuals, the "pleasantly senile", the mentally retarded and the emotionally depressed. Clearly there is a vast array of relevant distinctions between these conditions and thus there is a great danger inherent in stating a blanket conclusion such as, "Incompetent patients need not be given AHN." However, such statements often are used in court decisions and articles on this topic,^{17,18,19} and it is not clear that the authors are aware of the very broad population they are including, much less that their decisions might affect individuals who, although incompetent, are quite socially interactive. Thus caution needs to be used with the term "incompetent", and if a decision is meant to apply only to a subdivision of that class of patient, then that should be stated clearly.

Now that some pertinent terms have been clarified, attention is turned to their application in discussion of ethical principles.

Values Weighed in the Balance

1. Life. The value of life has long been held to be of very high priority. Our Constitution states that it is a self-evident right and one which requires safeguards to prevent its deprivation. However, in recent years there has been controversy over the valuing of life, particularly when other values

need to be weighed against it. In the debates over AHN, the opinions have ranged from viewing life as the ultimate value in medicine²⁰ to the outright rejection of the sanctity of life position.²¹

There is a view of life well-described by Richard McCormick which gives what I feel is a balanced approach.²² He emphasizes that the value attached to life is very high, yet it is not an absolute good. Life is valuable in itself and it is the condition which makes possible the attainment of other values. When the condition of life is such that other values are not able to be realized, then the duty to preserve life is modified. This approach avoids the trap of vitalism, in which life is seen as a value to be preserved in and of itself at all costs. This form of vitalism runs counter to the Judeo-Christian tradition of viewing life as a basic good, yet one to be sustained primarily as the condition for other values. Thus preserving life can be viewed properly as a *prima facie* duty, i.e., one which is weighted heavily, yet can be overridden when other important values conflict with it.

2. Capacity to Relate. The ability of a person to relate to his/her environment and to others is valued very highly, since this makes human relationships possible. It is through relationships that the essential identity of humans as social beings is realized, and that the values of love and care can be expressed. This concept becomes of importance in the debate over AHN, because many authors find that as this relational capacity is decreased the less heavily other duties (e.g., to preserve life) need to be weighted.

Here again McCormick's article gives helpful guidance.²³ If life is the condition which makes possible relationships through which love of God and neighbor can be realized, then the duty to sustain life diminishes with absence of relational potential. McCormick does not give specific criteria to delineate "relational potential", but he does give the example of an anencephalic infant as one who does not possess it and a Down's Syndrome infant as one who does. Between these two cases lie many others of varying potential for relationship. Although drawing lines of distinction between them may result in errors of judgment at times, he feels this does not nullify our need to make decisions. In unclear cases one should err on the side of life.

Seemingly Sound Approach

This approach seems basically sound, but the concept of relational capacity needs more concrete development. I believe that the amount of relational capacity necessary to keep in force the requiredness of AHN is minimal. In other words, even the smallest amount of relational capacity present (e.g., the ability to make eye contact, smile, feel the touch of another) should weigh heavily against discontinuing AHN. This is an important point to make, because as noted above, many authors and court cases, especially the *Conroy* case, apply their guidelines to "incompetent" patients whose abilities to relate vary tremendously. A schizophrenic

person, a child, a mentally retarded adult or a demented individual may each be incapable of deciding on their medical treatment and fit the definition of incompetent, yet this does not make them devoid of the ability to relate to others, and it does not make us unable to relate to them. If we are able to show our concern to a person, whether that be limited to a touch or smile, and have it given minimal recognition, then this is enough to warrant provision of care, all other factors (such as absence of pain) being equal. The ability to be totally cognizant of oneself as an entity and to be involved in mutual caring relationships is not the level of interaction necessary on the part of the patient. Our duty is to care, without expecting that it be reciprocated to the same extent. We can see this inequality of relationship in our care for normal infants who have minimal interactional skills, but whom it is quite possible to love. Why is this considered by some not to be possible at the other end of life? Granted the cases of a demented person and of an infant or small child are not equivalent. The tragedy of loss in the former and the potential for growth in the latter make the situations quite different. The element of hope for the future which the infant represents plays a significant part in the attachment of adults to the infant, which differentiates this dynamic from that with the demented elderly. Yet, in the moment, care may be able to be given and received in the same manner, and the value of that social interaction is, in that sense, the same.

Similarly, when this priority of relational ability is applied to the terminal patient, it is clear that the sole fact of one's having an incurable illness does not alter one's relational capacity. In fact, the need for relationships may be more keenly present. Thus when the statement by the AMA allows discontinuation of AHN for a "terminally ill patient whose death is imminent",²⁴ on that basis alone, it is devaluing the importance of relationships to that patient.

On the other hand, no level of interaction may be possible for a patient, as seen in the permanently comatose state. The patient may be totally unaware of environmental stimuli and have no cognitive function. In such a case the person does not have the ability to be aware of any care given to him or her and thus no relationship, even a very uneven one, can be sustained. Maintaining the physiologic state of this individual does not allow for our essentially social nature to express itself in relationship and thus it may not be warranted.

3. Relief of Suffering. To lessen suffering is one of the foremost goals of medicine. In discussing suffering, many of the same qualifiers used above regarding "burdensome" should also be used here, e.g., what type of suffering is it? Who is experiencing the suffering? If an incompetent patient requiring a feeding tube is not aware of his need for it and struggles against it to the point that constant restraints are used on him for reasons he does not understand, is this not suffering of another kind?

Often neglected in discussions of AHN is the fact that the suffering

inflicted by providing it and the suffering caused by withholding it both need to be considered. Thus it is not enough to find that providing AHN will result in suffering, if this is not balanced by looking at the suffering that will result if it is withheld. For example, will the patient experience pain or discomfort as a result of dehydration and malnutrition? If so, it would be extremely difficult to justify withholding it from that person. This dilemma is compounded by some authors who suggest that doctors should obviate this concern by medicating the patient so that he/she is anesthetized from the pain which may result from dehydration/starvation.^{25,26} Although admittedly a matter of judgment, this is the point at which I believe a line should be drawn, making unacceptable this option of anesthetizing patients to effect withdrawal of AHN. At this point, it too nearly approximates active euthanasia, and the slippery slope leading to it needs to be avoided. This proposal of providing anesthesia takes on a more "active" character because it combines two causative actions, i.e., both withdrawing the nutrition itself and altering the patient's perceptions in order to effect it. Also the process would directly deprive the patient of consciousness and relational capacity, which are primary values. If a person is aware enough to require anesthesia to relieve suffering, then it is likely this individual may also have relational capacity, and thus it is prudent to draw the line here precluding anesthesia. This would act to safeguard the important value of relational capacity and to avoid the slippery slope leading to the social effect of endorsing active euthanasia. Thus in conscious patients it would be very rare that discontinuing AHN would be acceptable.

Although some authors claim that permanently unconscious individuals could not be aware of any discomfort from a discontinuance of AHN,²⁷ it is not clear that we will ever prove or disprove this.²⁸ It seems that here a "leap of judgment" must be made, because practical decisions must be made on the best available evidence when infallible evidence is not available. Not taking a course of action because of lack of certainty may also be morally irresponsible. The evidence which we do have points to lack of pain perception in these patients, and it is acceptable to act on that assumption.

4. Symbolic Content of Feeding. It has been argued that there is a transcendent meaning present in the act of feeding, which "is the perfect symbol of the fact that human life is inescapably social and communal", and that discontinuing AHN in some cases would lead to a dilution of the social instinct to feed the hungry.²⁹ Although basically agreeing with these sentiments, I see the need to raise further questions: Does AHN always express compassion? If the patient is comatose, to whom is the act of feeding serving as a symbol? The answer to the first question is no, because the compassionate response depends on the context. For example, keeping a frightened, confused struggling incompetent patient continually restrained, resulting in decubitus ulcers and deep venous thrombosis in order to supply nutrition, may not be a compassionate response to that

situation. Also, supplying AHN to a permanently comatose patient to maintain a state in which no relational capacity is possible, but which creates great emotional and financial burdens on the family, may also be seen as lacking in compassion. Thus when asked whether we are obligated to provide symbolically significant treatment, I find the proper response to be that we are more obligated to care in fact, than to care in symbol, and that only by looking at the whole context of the patient can we judge the most caring act.

5. Patient Autonomy. In recent years, the value of patient autonomy in decision-making has been realized increasingly. It has become such a priority that when one tries to argue a position which places another value higher than autonomy, one is often accused of paternalism, which is assumed to be a derogatory declaration. It is not possible to discuss this fully here, but I wish to make the point that patient autonomy is not absolute, contrary to the implications of many court decisions and the statement of the AMA.³⁰ For example, if to comply with a patient's demand for autonomy would require us to assist in a suicide, then we are not morally bound to comply. If a court were to rule in favor of the patient's autonomy, we need not participate and our protest may be expressed by defending our position and by turning over the care of that patient to another physician who can, in conscience, follow that course.

Now that the major values at stake in the debate over AHN have been discussed, attention will turn to proposing an ethical framework to serve as a guide to appropriate balancing of these values in making treatment decisions regarding specific patients.

A Proposed Ethical Framework

As stated in the introduction, the method of a benefits/burdens calculus has been recommended by many as a tool to aid in decision-making regarding AHN. In this method, one looks at the treatment as well as the non-treatment options available to a patient, and assigns weight or priority to the benefits and burdens of each alternative. Then the course which is felt to result in a more favorable balance of benefit over burden is chosen. Before applying this formula, terms need to be defined and values delineated, as has been done in the earlier two sections of this essay. Then a method of prioritizing and weighing values should be clear in the mind of the decision-makers, so that they are aware of what they are valuing when they reach a conclusion, and that the decision reflects responsible value commitments. Such a method will be proposed here.

First of all, it should be realized that this method views the situation of the patient as a whole and does not focus on one specific aspect of his/her condition. For example, as noted above, if one only looks at the *means* used to supply AHN (e.g., a feeding tube) and decides that as such it is not burdensome, and on that basis alone concludes that AHN should be provided, one may easily overlook the fact that, in the context of this

specific patient, the means of tube feeding may be burdensome due to its repeated causing of aspiration pneumonia or pulmonary edema. Thus the whole context needs to be assessed to make appropriate decisions, because a procedure which may be benign in one patient may be burdensome in another.

A similar misapplication of the benefits/burdens calculus may occur when one declares that the value of biologic life can never be overridden. This type of declaration makes any balancing of values and contexts impossible, because metaphorically the scale is permanently tipped to that side. Granted that certain values may be given very high priority, (and this is appropriate), there yet should remain a remote possibility that some extreme condition may exist which could force one to allow even a high priority value to be overridden. There is an understandable temptation to make unbreakable rules, because there will be more uniformity of decision outcomes. For example, there is a tendency to want to draw clear-cut lines at one end of a spectrum or the other, so that there will be apparent clarity in decision-making. Thus one solution would be to place an absolute value on the preservation of life, making AHN mandatory in all cases. This proposal certainly makes decision-making "easier", but it is not so clear that this would result in the wisest or best possible decision when the totality of each case is considered. The fact that a line of distinction is difficult to draw does not mean it should not be drawn at all. The arena needs to be entered with appropriate humility and trepidation, but it must be entered.

Thus the basic approach is to weight values according to their priority and note how they apply in a particular case. The balancing of conflicting values involves the process of requiring a progressively more burdensome situation to justify the subjugation of a progressively more valued priority. The value system which I am proposing here puts a very high priority on life, and hence the duty to preserve life; thus providing AHN is generally indicated. However, the duty to preserve life is not absolute to the point of vitalism; rather it is subject to being overridden when there is no capability or potential for any form of interpersonal relationship, as in the case of permanent loss of consciousness. This leads to the discussion of another highly prized value in this system, i.e., relational capacity. As explicated above, this is of importance because of its implications in light of the inherent social and communal nature of human beings and of their obligations to care for one another, particularly when one member is relatively helpless. Thus it is not necessary for a patient to be competent or in a mutual reciprocal relationship with others in order to warrant continued AHN. A minimal amount of interactional ability is all that is required, all other factors being equal. Using this same approach, it is clear that withholding AHN from a patient, solely because it is known that he/she has a terminal disease, would not be appropriate. Such a person has continued opportunity to engage in interpersonal relationships, and thus the duty to preserve life is not overcome. It is more important, in these

cases, to provide support and care to these persons who are still part of our community and cognizant of our concern.

Superimposed on the duties to preserve life and to maintain human relationships is the duty to relieve suffering, which includes both that suffering caused either by providing or by withholding AHN. Depending on the situation, this could override the other duties. For example, if a patient is very near death (i.e., expected in less than one month), has minimal relational capacity, and the feeding tube or parenteral nutrition is causing pain and medical complications, it could be appropriate to withhold AHN. Similarly a demented patient who does not understand the reason for the AHN may require sedation and physical restraint which would cause more suffering in the form of fear, struggling, physical injury, lack of freedom and an even more clouded mental capacity due to sedation. Thus, in this case, diminishing suffering might preclude the duty to preserve life. There is also a very strong duty to not inflict suffering, or in common parlance, to "do no harm". This duty could tip the balance so that we may continue AHN in a patient who otherwise might not require it, yet would experience pain if it were withheld.

There is also the value of patient autonomy to be considered, which, as argued above, is not an absolute right. In the case of incompetent patients, the courts generally hold that decisions should be made using the "substituted judgment" standard, i.e., choosing what the patient would wish. However, since autonomy is not absolute, I would favor, as do Dresser and Boisubin, that the "best interests" standard be used, which may include within it evidence of the patient's former wishes.³¹

With this system of priorities now better defined, we will come to listing some of the guidelines which flow from it.

Resultant Guidelines

In light of this discussion, some general guidelines can be given to assist in decision-making regarding AHN.

1. It must be made clear that even when it is permissible to withhold AHN, it is not necessarily mandatory to do so.

2. Decision-making must include discussion with the patient, or, in the case of an incompetent patient, the family or guardian. The incompetent patient's prior wishes should be considered.

3. Guidelines should not make blanket statements regarding incompetent patients, since this term includes too broad a population with varying conditions.

4. AHN need not be effecting a cure in order to be deemed appropriate therapy, i.e., maintaining a condition is a sufficient level of "effectiveness" in some cases.

5. AHN is a medical treatment, but this does not imply automatic equivalency to all other forms of treatment. Therapy options lie on a continuum and should be considered as such, with AHN generally falling at the benign, noninvasive end of that spectrum.

6. The class of "dying" patients should be narrowed to those whose death is expected in approximately one month.

7. If providing AHN would be futile (e.g., if intestinal disease prevented absorption and a clotting deficiency prevented intravenous fluids), then it need not be provided.

8. In permanently comatose patients, it may be permissible to withhold AHN.

9. If an incompetent patient still possesses the capacity to relate to an even minimal extent with others, then AHN generally should be provided.

10. If discontinuing AHN would cause pain or discomfort, the patient should be fed. Giving medications to anesthetize the patient to such pain is not an acceptable option.

11. It may be, at times, acceptable to withhold AHN from an incompetent patient who does not understand the need for it and thus resists it, requiring continuous physical and/or chemical restraint. (If, after discontinuing AHN, the patient experiences apparent resultant discomfort, the decision may need to be reassessed.)

12. In the case of patients who are terminal (by any definition of that term), AHN should not be withheld on the basis of that diagnosis/prognosis alone.

Conclusion

In summary, then, it is clear that in using the benefits/burdens calculus in making decisions about AHN, each case must be evaluated in its own context. Thus blanket legislation on these situations should be avoided. Ethically consistent decisions in the clinical situation can be reached, however, if one establishes a priority of values and a method of approach. Such a system has been proposed here, and by applying it to individual cases, decisions can be reached with a clear understanding that what is most valued is interpersonal relational potential, with biological life as a supporting value, and pain as a clear disvalue. Rather than merely listing legally permissible treatment options, we should understand our reasoning process behind our decisions so that when applied in professional decisions, it will cohesively reflect our most deeply held values.

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