May 1994

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Recommended Citation

McCarthy, Jeremiah J. (1994) "Caring for the Critically Ill Patient in a Persistent Vegetative State: Must Nutritional and Hydration Support Always be Provided?," *The Linacre Quarterly*: Vol. 61: No. 2, Article 7. Available at: <https://epublications.marquette.edu/lnq/vol61/iss2/7>

Caring for the Critically Ill Patient in a Persistent Vegetative State: Must Nutritional and Hydration Support Always be Provided?

by

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There is a searing and acute suffering involved in the realization that a loved one, seriously brain-injured in an automobile accident, has lost forever the functional integrity of the upper hemispheres of the brain. As a consequence of this profound insult to the brain, the individual is deprived of the capacity for speech, conscious interaction, and the vital communication we prize in human relationships. All that remains is the functioning brain stem which controls heartbeat and respiration. Provided with nutritional and hydration support, the patient who is otherwise "biologically tenacious"¹ will continue to live a prolonged and relatively comfortable existence in this condition known as "persistent vegetative state" (PVS). This medical condition accurately describes the plight of several well known cases that have been in the forefront of a vexatious and troubling debate among ethicists and health care professionals. Names such as Nancy Cruzan, Paul Brophy, and Nancy Jobes have dominated media and public policy discussions.

In this essay, I propose to examine the debate among Roman Catholic moral theologians and to review with some care the crucial distinctions that have been operative in these moral appraisals. In addition, several episcopal conferences have made significant interventions on this issue including, among others, the bishops of Pennsylvania, Texas, Washington and Oregon.² I will refer to these statements at the end of the paper, but for the initial purposes of my argument I will summarize the most recent statement of the National Conference of Catholic Bishops operating through its public policy arm, the United States Catholic Conference. This response of the American Catholic hierarchy is captured in its long awaited paper, *Nutrition and Hydration: Moral and Pastoral Reflections*.³ The proponents

as well as the opponents of artificially delivered nutrition and hydration (ADNH) have appealed to the same ethical criteria but with differing emphases and with different conclusions. While the majority of American Roman Catholic moralists continue to support withdrawal of ADNH, nonetheless, the arguments of those who oppose withdrawal of ADNH present critical challenges. Needless to say, the debate has created a public policy controversy, and the Bishops' Statement endeavors to stand in what Richard McCormick calls "the critical middle."⁴

My thesis is that the debate discloses the inevitable collision of divergent perspectives concerning the basic methodological presuppositions of Catholic moral theory. Briefly stated, these perspectives are a "proportionalist" calculus of moral norms and a deontologically influenced natural law assessment of moral norms. At the risk of considerable oversimplification by a proportionalist calculus, I am referring to a process of weighing or "measuring" competing values in a moral decision which factors in moral rules or norms, and is grounded in a conviction that the concrete details of a particular case are ultimately determinative for assessing the applicability or relevance of the moral rules which are invoked. Similarly, by a "deontologically influenced natural law assessment," I am referring to a process of moral analysis which stresses a moral order discovered by human reason (i.e. "natural law"), and develops moral principles that cannot be overridden by appeals to changing circumstances in the particular case, hence the adjective "deontological" which means "duty" or "obligation."

In my view, the impasse discloses not so much the failure of these different approaches to casuistry in addressing ADNH, but rather the need to attend to the narrative description of the persistent vegetative state patient which is inscribed in the critical distinctions invoked by the moralists. Attending to such notions as care, comfort and solidarity with the weak may suggest a more fertile common ground for conversation. Leslie Rothernberg has raised the need to move to these considerations in his insightful review of the Brophy case.⁵

Accordingly, I plan to argue in three steps: first of all, a brief summary of the moral positions related to ADNH as outlined in the Statement of the American hierarchy; secondly, some critical questions with respect to the interpretation and application of moral criteria; and finally, the value of narrative description in order to pose some questions and challenges.

I. April, 1992 Statement of the NCCB.

The Statement begins with an appeal to fundamental Catholic convictions regarding life as a gift entrusted to human beings, a gift which entails the obligation of proper stewardship. On this rendering, euthanasia, understood as any action or omission with the express intention of directly ending the life of a human being, is expressly forbidden.⁶ Moreover, suffering is viewed as a "fact of human life" and can be alleviated as necessary to assure the comfort of the individual.

The duty to care for one's life is an application of the principle of stewardship and the exercise of this stewardship does not entail recourse to remedies deemed

to be "extraordinary" or "disproportionate," that is, remedies which do not offer a "reasonable hope of benefit" or are viewed as offering excessive burdens. A consultative process is advised in making the determination about the withdrawal of treatment with due regard given to the various roles of physicians, patients and families. The final stage of the dying process does not require the use of every available means to sustain life and such measures can be ethically foregone. Death is seen as an integral part of human life and must be accepted with equanimity and faith.

The document sees life as a gift and a gift that must be treated with dignity and respect. Any form of discrimination or violation of the rights of every human person regardless of aptitude or disability is seen as a transgression of the principle of justice. With these general principles in place, the document moves to the specific issue of ADNH.

There are seven questions posed to frame the response of the instruction. The document endeavors to make several clarifying responses in the light of these questions. The first question asks whether withholding or withdrawing ADNH is always a direct killing. In response, the instruction avoids two extremes. On the one hand, an omission can be a form of direct killing because it withholds appropriate treatment in order to cause the death of the patient. On the other hand, not every omission need be construed as an act of euthanasia since the intention of the omission may legitimately be understood as the withholding of a remedy which is of "limited usefulness to the patient or unreasonably burdensome for the patient and the patient's family or caregivers."⁷ The instruction then notes that under some circumstances withholding ADNH is done precisely because the patient is not dying and is perceived as "having as unacceptably low 'quality of life' or as imposing burdens on others."⁸

The second question touches upon the vexing conversation of whether ADNH is a form of treatment or care. The complexities of the patient's condition make this distinction difficult and the document reiterates the traditional appeal to the criterion of the burden/benefit test in order to guide the decision in the form of the following principle.⁹

Out of respect for the dignity of the human person, we are obliged to preserve our own lives, and help others preserve theirs, by the use of means that have a reasonable hope of sustaining life without imposing unreasonable burdens on those we seek to help, that is, on the patient and his or her family and community.

Questions three and four specifically address what is meant by the benefits and burdens of medically assisted nutrition and hydration. Among the benefits are the sustenance of human life, the provision of necessary care particularly for those likely to benefit from a possible cure, and the prevention of unnecessary suffering from dehydration, hunger and thirst in imminently dying patients. With respect to burdens, the document repeats the criteria offered by several Catholic theologians published in the journal, *Issues in Law and Medicine*, Winter 1987.¹⁰ Specifically, medical treatment is regarded as burdensome when it is "too painful, too damaging to the patient's bodily self and functioning, too psychologically repugnant to the patient, too restrictive of the patient's liberty and preferred

activities, too suppressive of the patient's mental life, or too expensive."¹¹ Normally, the patient is the one to make this determination, but assistance from health care professionals should be sought.

The document identifies "physical risks and burdens" which depend upon the nature of the treatment itself, and the condition of the patient. Less burdensome measures should be sought rather than an outright dismissal of ADNH particularly for PVS patients whose care is more easily managed by recourse to ADNH. Question four then addresses the assessment of psychological and economic burdens.

Mere "repugnance" is not a sufficient warrant for withdrawing treatment. Rather, the patient should be assisted with counseling and other interventions to appreciate the gift of life. Secondly, the document emphasizes the importance of "reasonable" wishes of the patient and the family underscoring the invaluable assistance of medical professionals and family members in reducing the fears experienced by the patient. Moreover, solid medical data is available indicating that not all patients find the provision of such measures to be inherently "repugnant." However, the more substantive discussion in the document is devoted to the analysis of economic burden and the question of "quality of life" criteria.

The document offers a helpful distinction between an altruistic intention on the part of a patient not to impose excessive financial burden on family members and directly intending death from removal of ADNH. Secondly, macro-ethical questions about the allocation of resources should not be assumed to have reached the level of clarity or specificity to determine decisions at the individual level. Thirdly, while the provision of tube feedings is generally inexpensive, the ancillary care that is required to sustain patients is quite expensive and burdensome. The instruction clearly acknowledges these difficulties and does not underestimate them. Nonetheless, the document asks caregivers to think through the reasons for withdrawal decisions. Are they performed because of the burdensomeness of ADNH or because the patient's continued survival in a diminished capacity causes the burden upon others? Rather than relying upon the withdrawal of ADNH to assure the desirable outcome of alleviating the "total burden of caring for the patient," society should make appropriate provisions for the financial, emotional and supportive services needed by those who need long-term care.

Question five asks what role should "quality of life" play in our decisions? The response of the document is a reaffirmation of the intrinsic dignity and equality of every human life. The sanctity of human life precludes any prejudicial assumption that persons with disabilities are to be treated with less respect or protection. If the "quality of life" consideration is invoked, three observations are in order:

- (1) Each patient's quality of life should be improved by measures which remove needless suffering.

- (2) Treatment may be foregone if it creates new and serious additional burdens upon the patient. Again, the reason for foregoing treatment is not the disability of

the patient, but the burden of the additional treatment.

(3) If the patient is experiencing a disabling incapacity to tolerate the provision of ADNH, less invasive measures should be taken to alleviate the burden for the patient.

It is important to note that the document carefully acknowledges a limited role for the place of "quality of life" considerations, but underscores that since euthanasia is often furthered by appeals to the notion of "quality of life," the operative control must be recourse to the "sanctity of life" of each individual. Whether or not "quality of life" can be rescued from its more deadly implications is at the heart of a significant conversation in the ethical literature, and I will address this matter in the latter section of the paper.

Question 6 turns to the more specific question of whether PVS patients constitute a "special case." The document gives a helpful appraisal of the key issues of agreement among theologians on the question. There is consensus that the life of the unconscious patient is to be treated with inherent dignity and value. Direct killing is forbidden. Moreover, there is a consensus that the debate does not concern patients whose condition is other than PVS, i.e., patients with Alzheimer's Disease, the severely demented and so on. The critical issue of disagreement is with the PVS patient.

Those who argue for the removal of ADNH for PVS patients proceed by establishing that the burden/benefit test applies to the total condition of the patient, and that the critical judgment rests upon the appraisal given to the physical life of the patient. Physical life is judged not to be the highest good of the patient, but rather as a valuable good subordinate to the capacity to achieve the purposes of life's goals. Therefore, since PVS patients are constitutionally incapable of ever realizing the higher, interactive expressions of consciousness, there is no obligation to sustain them in this condition, and all life-support measures, including ADNH, can be withdrawn. The intention in doing so is not to end the life of the patient, but to allow an underlying fatal pathology to take its course and to circumvent the excessive burden of life-support maintenance. Therefore, no direct killing of the individual occurs, rather, the natural dying process is allowed to unfold.

On the other hand, those who argue against the withdrawal of ADNH for PVS patients contend that the assumption that human, physical life is not a positive good in and of itself would set into motion a dangerous precedent. Human, physical life, in other words, cannot be construed instrumentally, that is, as a means to achieve other purposes, including such purposes as "life's higher goals."¹² As William May contends, "human life is an intrinsic good of persons; it is not merely an *instrumental* good, a good *for* persons."¹³ The assessment of burden, moreover, requires qualification. PVS is a severe neurological disability, not a fatal pathology. Because nutritional support can be provided and does provide the minimal benefit of maintaining the patient's physical life, ADNH is not extraordinary care and should be provided as an acknowledgment of the patient's inherent dignity and worth as a person.

Clearly, there is an impasse between these two positions, and the statement

finds that recourse to probabilism is not a satisfactory resolution. This tradition has maintained that the presence of reasonable and equally compelling moral appraisals affords the individual the freedom of choice to follow the most persuasive or "probable" course of action. However, there is a critical caveat, namely that in matters dealing with the value of human life, the "safer" course of action must be followed. Rather than advocating the route of moral probabilism, the statement reaffirms key values including the recognition of excessive burdens as well as the intrinsic dignity of human life. The statement strives for a middle course, a course which recognizes the complexity of the issue, advocating prayerful discernment, and endorsing further research.

The document expresses concern that an entire class of patients, namely PVS patients, be placed at risk because they cannot be restored to optimal cognitive functioning. The document relies upon the lack of clear scientific criteria for the diagnosis of PVS, the lack of conclusive evidence that PVS patients experience pain, and the fear that PVS patients are likely to be dismissed as "non-persons or as undeserving of human care and concern."¹⁴ Finally, the concern is raised that even well-meaning and careful moral arguments can be "misinterpreted, broadened, and abused by others to erode respect for the lives of some of society's most helpless members."¹⁵ The conclusion of the statement deserves full citation:¹⁶

In light of these concerns, it is our considered judgment that while legitimate Catholic moral debate continues, decisions about these patients should be guided by a presumption in favor of medically assisted nutrition and hydration. A decision to discontinue such measures should be made in light of a careful assessment of the burdens and benefits of nutrition and hydration for the individual patient and his or her family and community. Such measures must not be withdrawn in order to cause death, but they may be withdrawn if they offer no reasonable hope of sustaining life or pose excessive risks or burdens. We also believe that social and health care policies should be carefully framed so that these patients are not routinely classified as "terminal" or as prime candidates for the discontinuance of even minimal means of life support.

The seventh and final question of the statement moves beyond the narrow question of who is the appropriate decision-maker to focus on principles for good moral decision-making which will include the interests and competencies of the patient, proxy decision-makers, health care professionals, and even the interests of society as a whole.

The foregoing summary of the NCCB statement helps to frame the complexity of the issues involved in the care of PVS patients. In the following section of the paper, I propose to explore some critical points of methodological conflict in the argument.

II. Critical Tensions in the Moral Argument

It is helpful to locate the history of the moral argument in Roman Catholic moral theology within the larger context of developments related to the management of critically ill patients. In a recent essay, Charles Sprung, M.D., argues that changing attitudes and practices in foregoing life-sustaining treatment

are leading ineluctably to a greater permissiveness with respect to euthanasia in this country.¹⁷ Sprung's thesis is not a simplistic invocation of the slippery-slope and its attendant dangers, but a thoughtful appraisal of the current societal and economic factors which influence critical-care decision making. I think Sprung accurately analyzes the current state of affairs, but more importantly, I think his analysis focuses attention upon the presuppositions that are often overlooked in the detailed moral casuistry surrounding critical-care decision-making, and this insight is applicable to ADNH. According to Sprung:¹⁸

If a treatment is deemed futile not because it will fail technically but rather because the life saved is deemed not worthy of being saved, a moral judgment and not a medical judgment has been made. Judgments concerning the social worth of a patient's life have traditionally been considered unacceptable criteria for forgoing care.

If we follow Sprung's lead by focusing upon the presuppositions which are brought both to the appraisal and application of moral norms, I think the following "critical tensions" emerge as the neuralgic core of the ethical impasse: (1) Can "quality of life" considerations be sufficiently re-worked to serve as reliable criteria for the assessment of benefit and burden? (2) Can the concepts of "personhood" and "biological life" be distinguished without collapsing into a form of dualism? (3) Does the withholding of ADNH for PVS patients involve us in a re-description if not a re-definition of death? If so, what are the public policy implications of such a move? (4) What role should autonomy play in the refusal of ADNH, and under what conditions? I think these four questions disclose enduring tensions in the moral casuistry surrounding the issue, and, after a brief analysis of each of these considerations, I offer a concluding reflection on narrative description as a way of dislodging the ethical impasse.

First, several ethical analyses have attempted to use the notion of "quality of life" as a mechanism for adjudicating the trade-off of burdens and benefits in the continued provision of ADNH for PVS patients. Lawrence Holst, for example, contends that quality of life (QL) has emerged as a decisive factor because of the capacity of modern medicine to maintain biological life and the "recognition that individuals derive essential meanings and personal fulfillments in life from a variety of sources, many of which transcend biological existence."¹⁹ Holst further argues that the QL criterion means "life is not an absolute good, but rather a relative good that enables one to pursue other goods."²⁰ Moreover, Holst recognizes that QL can be "very relative, subjective, soft and imprecise. . . But what is the alternative?"²¹

It is worth noting that the critical issue for Holst, and echoed by other moralists including Richard McCormick and Kevin O'Rourke, is the contention that life (understood as physical, biological life) is not an absolute but a relative good.²² The point behind this contention is the desire to avoid a crude vitalism as the moral lever governing treatment decisions. However, there is the enduring danger that physical, biological life will be undervalued to the detriment of those who are developmentally disabled or cognitively compromised.

Recognizing these pitfalls, Thomas Shannon and James Walter have

undertaken a valiant effort to rescue the notion of QL from its more sinister implication that some lives are deemed "unworthy" of protection and respect.²³ The authors value the physical life of every individual as worthy of equal protection and not as a "conditional" value (*bonum utile*, or good which is viewed instrumentally) dependent upon some other standard. Nonetheless, this physical good or *bonum onticum* (ontic good or *prima facie* value independent of any ancillary values which it may serve), must be distinguished from personal life (personhood).²⁴ Pursuing this line of thought, the authors argue that "quality" is not to be understood as an attribute or property of life, but rather should be understood as referring to the *relationship* (authors' emphasis) "which exists between the medical condition of the patient, on the one hand, and the patient's ability to pursue life's goals and purposes understood as the values that transcend physical life on the other."²⁵ QL, then, is understood not "consequentially," that is, because patient X possesses or does not possess some desired attribute, but "teleologically," that is, not on the basis of some desired quality or attribute, but on the "relationship between the patient's overall condition and his/her ability to pursue life's goals and purposes."²⁶

While this careful and thoughtful essay has much merit, I am not sure that it is a fully successful enterprise. My difficulty lies with the disjunction between physical life and personhood. According to John Grondeleski, such a disjunction is tantamount to equating personhood with a desired level of consciousness. This perspective has implications for the benefit/burden test:²⁷

The traditional benefits/burdens test asked whether a particular means was burdensome; now, it is not the means but the life itself which is weighed. Life is no longer self-justifying; it must meet a certain standard, a certain level of communicative consciousness, or that life is declared burdensome.

Philip Smith, a Thomistic philosopher, reviews the notion of personhood in relationship to the PVS patient, and concludes that the functional impairment experienced by the PVS patient is not a warrant for concluding that the soul, understood as the organizing principle which unifies the many capacities of the body into an integrated system, is separated from the body by the onset of PVS. In Smith's view, this contention introduces an "erroneous dichotomy between person and body."²⁸

I am troubled by the implication that the quality of life of the PVS patient loses its protectability when there occurs the "permanent absence of consciousness and the ability to engage in human interaction," a verdict reached by sixteen theologians at a conference held by the School of Theology at Claremont in December, 1989.²⁹ Therefore, my first "critical tension" in the moral debate is focused on the issue of quality of life. To the extent that this notion requires a disjunction between physical life and the notion of personhood, I do not think that it successfully avoids the objection that it undercuts the moral valence of the notion of personhood to ensure equality and protectability.

My *second* critical tension builds upon the first and focuses upon the issue of dualism in the disjunction between physical life and personhood. According to Philip Smith, after a thorough analysis of the criteria for ascertaining the

neocortical status of the PVS patient, PVS patients are not dying patients because the intact brainstem maintains vegetative activities including spontaneous respiration. This level of impairment does not constitute sufficient damage to indicate the soul's departure and thus to cause death.³⁰ Such patients "retain enough functional integrity to be compatible with the human soul," and Smith wisely points out that though they are not dying this conclusion does not resolve the question of whether or not they should receive ADNH. Nonetheless, the critical caution that he raises and that I also endorse is that the solution must not move in the direction of "defining them out of existence."³¹ Grondeleski adds that dualism appears to be an inescapable feature of the positions adopted by Richard McCormick, John Paris, and Edward Bayer.³²

For them the decisive question is the absence of an explicit ability to express interaction with other persons. This author cannot see how such an approach differs from a Cartesian dualism which reduces the body to a mere subpersonal appendage of the "person" (scil. "consciousness"). Nor can this author see how Cartesian dualism could be reconciled with a Catholic anthropology.

There appears to be the same form of dualism in the rationale provided by the Claremont theologians in their statement endorsing withdrawal of ADNH for PVS patients. Providing sustenance to these individuals is tantamount to "artificially sustaining metabolism."³³ In my view, such a perspective effectively dehumanizes these damaged persons and removes them from the human family. Whether or not withdrawal of ADNH is appropriate, my concern is that the reason for such decisions not rest on the faulty presupposition of a dualist anthropology which de-values and harms PVS patients and those who are similarly, though differently compromised, such as Alzheimer's patients and those with severe cognitive and mental impairments.

My *third* critical tension is related to the issue of dualism and concerns the implications associated with re-descriptions or re-definitions of the meaning of death. Daniel Wikler argues for a re-consideration along these lines by suggesting that PVS patients are really suffering from amentia, "an absence of everything for which people value existence. Its position as the limiting case on the continuum-the patient for whom all life has ebbed-is what justifies regarding it as death."³⁴ Wikler's proposal to redefine death to include PVS would perhaps ease the anguish of treatment decisions but it is hard to comprehend what criteria would prevent the escalation of such an approach to encompass others under its umbrella. Wikler's distinction of "psychological" death from "bodily" death relies upon a dualistic construal of the human person and represents, in my view, a most unwise departure from the integral conception of brain death as death of the whole brain, including the lower brain stem. Groups who work with persons with varying degrees of physical and mental disability are rightly concerned about such overtures, and I judge that efforts to re-define brain death criteria to address the difficulties associated with PVS patients are unwarranted and unjust.³⁵

Granted the above considerations, my *final* critical tension deals with the issue of autonomy and the ability of the PVS patient or surrogate decision-maker to

forgo ADNH. Does the availability of the technology require its use, and can an individual refuse ADNH without incurring the moral objections against withdrawal? Germain Grisez, in an article retracting an earlier endorsement of withdrawal of ADNH, and also written in counterpoint to Kevin O'Rourke's article supporting withdrawal of ADNH, nonetheless suggests that such an individual may refuse to accept ADNH. Grisez contends:³⁶

Competent persons who envisage the situation of being comatose, and who clearly and freely reject food in that situation should it ever come about, need not be choosing to kill themselves. They can, instead, be choosing both to avoid being kept alive by a method toward which they feel psychological repugnance and to free others of the burden of the cost of caring for them. If people who have made and adequately communicated such a decision become comatose, others can comply with their choice without in any way violating human solidarity with them. Under these conditions, not caring for comatose persons is not abandonment. Rather, by respecting the comatose person's wishes, others express their benevolence, affirm that person's dignity, and maintain the bond of human communion with him or her.

Grisez is quite clear that such a decision does not extend to those who have not made such a determination, and he is concerned that cost-containment pressures not dictate the decision. My problem with Grisez's formulation is the issue of how and in what sense an appeal to autonomy can "trump" other ethical considerations including the moral integrity of the means used to achieve one's desired ends or purposes. Even though an appeal to "psychological repugnance" to justify refusal of ADNH appears to be ruled out in the NCCB Statement, nonetheless Grisez's proposal warrants another look. Perhaps a more effective strategy might be to focus on the moral virtue of Magnanimity" or "large-souledness" as a possible warrant justifying such a refusal of life-sustaining treatment. In other words, I would not want to rule out the possibility of self-sacrifice as an act of moral heroism on the part of an individual (or a duly empowered surrogate decision-maker) as a justification for refusal to accept ADNH. But, more importantly to my mind, Grisez's analysis indicates a need to attend to a critical issue with which I conclude my remarks.

This issue is the need to articulate with more clarity the intellectual and moral commitments we bring to the issue of ADNH for PVS patients. After perusing the many careful and sensitive articles on this question, I am left with the impression that there is a great hunger for the decisive and definitive application of the available moral principles that will deliver us from the impasse on the issue. It is precisely here where I think our energies are misplaced. Allow me to suggest an alternative construction of the question which may yield more dividends in our approach.

III. Towards a Narrative Description of Critical-Care Decision-Making

Edmund Pincoffs in his insightful and landmark essay, "Quandary Ethics" suggests that it is precisely the conception that ethics is chiefly about problems and decisions that misleads us in the effort to resolve moral dilemmas.³⁷ The insistence upon principles and careful casuistry as conceptual tools to aid us in the quest for moral wisdom is certainly appropriate. However, the enduring temptation in this pursuit is the tendency to think that life is a series of crises that

must be managed successfully. Neglected in such a construction of the moral enterprise is the equally salutary admonition that there are dimensions of life that cannot be managed or easily controlled within the confines of neatly defined moral categories. Issues such as suffering, death, and the unpredictable contours of historical existence elude tidy categorization. Moreover, many aspects of life cannot be construed within a "decisionist" or "quandary" framework. It is difficult, for example, to conceptualize the obligations that we inherit by being members of a biological family unit as choices or decisions amenable to a rigorous moral logic. As Stanley Hauerwas has observed in the whimsical title of one of his essays, "Must a Patient be a Person to be a Patient, or He isn't much of a Person, but He's still My Uncle Charlie."³⁸ Hauerwas's point is that recourse to an abstract notion such as "personhood" may not be sufficient to capture the distinctive and particular obligations that flow from our concrete human relationships.

The acknowledgment of moral complexity and the more diffuse considerations which encapsulize every human life should not be understood as an abdication of critical moral reasoning. Rather, the acknowledgment of questions which defy our hunger for swift resolution suggests a different approach to moral casuistry. Critical, careful moral reasoning is still essential, but the purpose of this casuistry is not so much to provide us with unimpeachable verdicts of rightness or wrongness so much as it is to test the limits of our construals of what is appropriate for us to do. Moral principles, valuable as they are, are but ethical shorthand. They capture in summary form a vast array of human experience that is mediated through the crucible of tested wisdom.

No moral issue exists in a vacuum. The crisis of how we should care for the PVS patient merely brings in sharper relief the crisis of how we should care for any suffering person. Perhaps we need to re-focus the debate on ADNH. Suppose we ask not "whether and how ADNH should or should not be provided to PVS patients," but "what kinds of skills must we possess in order to be faithful and caring companions of sisters and brothers who are in the persistent vegetative state? By framing the issue in this fashion, I am suggesting that antecedent to the application of moral principles is the need to address the context of meaning in which we pose the question. Recourse to "quality of life," "benefit/burden," or other such principles to resolve this vexatious issue is but the beginning of the process.

In other words, I am suggesting that inscribed in the formulation of these principles is a story or narrative of human life and its meaning that is often overlooked in the legitimate quest for clear guidelines for action. With respect to our brothers and sisters who are in the persistent vegetative state, have we dealt sufficiently with the story of their lives and their connection with us? Does not the fact that they are cognitively compromised confront us with our deepest fears of our own fragile purchase upon the control that accrues to the cognitively powerful? Because we find their wounded plight troubling, have we explored sufficiently the reasons why we are troubled by their "biological tenacity?" Have we probed sufficiently our own fears of mortality, and our own discomfort in

living with those who most acutely manifest our frail humanity? I raise these questions not as "trump" cards, but rather to suggest that attention to these larger "narrative" considerations may be a valuable contribution to the debate on care for patients in the persistent vegetative state.

In conclusion, the purpose of this essay has been to review some of the issues in the vast debate on the care of PVS patients and the provision of ADNH. I find the reasoning and cautions of the most recent NCCB statement to be persuasive, though as a signatory of the 1987 statement published in *Issues in Law and Medicine*, I stand by a more conservative policy of withdrawal of care for these individuals. I think the issue goes beyond the polemics of casuistry, whether of "proportionalist," "deontological," or "natural law" formulation. Questions of ultimacy are unavoidable even in a culture shaped by the twin forces of Enlightenment reason and technical prowess. These questions provoke us to explore the larger meanings by which we live. The crisis of the persistent vegetative state patient challenges us to consider this larger narrative, this larger story of life's ultimate meaning. I prefer to think that this tale implies our solidarity and care for these individuals, and that we should think carefully before we withdraw from them the companionship that the cognitively powerful owe to those who are less fortunate, but no less our sisters and brothers.

Some issues that are worth further exploration occur to me as a result of this exercise, and I raise them to enrich our conversation with our distinguished respondents. First of all, it is interesting to contrast the differing emphases of the statements drafted by the bishops of Texas, Pennsylvania, Oregon and Washington. The Texas statement is perhaps the most permissive of the three with respect to the PVS patient since it states that "these individuals are stricken with a lethal pathology which, without artificial nutrition and hydration, will lead to death."³⁹ This statement can certainly be controverted on empirical grounds, but nonetheless it provides a warrant for a policy of withdrawal of ADNH. The Pennsylvania statement is the most restrictive of the three, and is similar in most respects to the 1987 statement drafted by William May, et. al.⁴⁰ The Washington and Oregon Bishops take a more cautious mediating position that presumes the value of ADNH for PVS patients, but then suggest that public policy may require a less restrictive application of this presumption:⁴¹

Because the wishes of the individual and the family are so important in this delicate area, it has proved difficult for legislators to formulate adequate legislation and for judges to give decisions which take into account the complex moral dimensions involved. People who argue for more restrictive legislation are legitimately concerned about a "slippery slope" mentality, in which the legally sanctioned option to withdraw life-sustaining treatment such as nutrition and hydration might encourage those in our society who are determined to promote euthanasia. At the same time, were our laws not to permit the morally justified withdrawal of artificial nutrition and hydration from any permanently unconscious patients, many are convinced that public sympathy for the unnuanced position of the pro-euthanasia movement would be encouraged.

My first question, then, is the following: does the permissibility of withdrawal of ADNH lead ineluctably to the euthanasia "slippery slope?" My second

question is concerned with the understanding of "burdensomeness." Can "burdensomeness" be expanded to include the interests of third parties (e.g.: family members, society) so that a decision to withdraw ADNH is not based on an unwarranted quality of life assessment of the PVS patient, but rather on the calculus of excessive "burden?" Thirdly, can there be a legitimate appeal to patient autonomy along the lines suggested by Germain Grisez, or does such an appeal ultimately erode the respect that is owed to the PVS patient?

References

1. A phrase used by Daniel Callahan to describe the plight which confronts these patients in his essay, "On Feeding the Dying," *Hastings Center Report* 13 (October, 1983):22.
2. These statements are significant for the debate in that they reflect the complicated moral analysis involved in the management of PVS patients. The Texas statement can be found in *Origins* (June 7, 1990) Vol. 20, No. 4, pp. 53-55. The Pennsylvania Bishops statement is reproduced in *Linacre Quarterly*, 59 (February, 1992): 8-30, and the Oregon and Washington Bishops Statement is reprinted in *Origins* 21 (November 7, 1991): 346-352.
3. *Nutrition and Hydration: Moral and Pastoral Reflections*, Committee for Pro-Life Activities, National Conference of Catholic Bishops, April 1992.
4. Richard McCormick, *Health and Medicine in the Catholic Tradition, Tradition in Transition* (New York: Crossroads, 1984): 160.
5. Leslie Rothenberg, "The Dissenting Opinions: Biting the Hands That Won't Feed," *Health Progress* 67 (December, 1986): 38-46 and pp.99.
6. The text reiterates long-standing church teaching as expressed in the June, 1980 *Declaration on Euthanasia* promulgated by the Congregation for the Doctrine of Faith.
7. NCCB Statement, op. cit., p.2.
8. Ibid.
9. Ibid., p.3.
10. William E. May, et. al., "Feeding and Hydrating the Permanently Unconscious and Other Vulnerable Persons," *Issues in Law and Medicine*, 3 (Winter, 1987): 203-217.
11. Ibid., p.208.
12. This notion has been elaborated by Richard McCormick in several places, including his landmark essay, "To Save or Let Die," *America* 130 (1974): 6-10.
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19. Lawrence E. Holst, "Withholding Nutrition and Hydration: Some Old and New Questions," *The Journal of Pastoral Care*, XLV (Spring, 1991, No.1):3-14, at p.9.
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23. Thomas A. Shannon and James J. Walter, "The PVS Patient and the Forgoing/ Withdrawing of Medical Nutrition and Hydration," *Theological Studies*, 49 (December, 1988): 623-649.

24. Ibid., p. 635.
25. Ibid., p. 637.
26. Ibid.
27. John M. Grondeleski, "Removal of Artificially Supplied Nutrition and Hydration: A Moral Analysis," *Irish Theological Quarterly*, 55 (1989): 291-303, at p. 297.
28. Philip Smith, "Personhood and the Persistent Vegetative State," *Linacre Quarterly*, (May, 1990): 49-59, at p. 57.
29. The Conference Statement appeared in the *Los Angeles Times* editorial page, December 11, 1989.
30. Smith, op. cit., p. 56.
31. Ibid.
32. Grondeleski, op. cit., p. 296. Lisa Cahill in her review of the nutrition/hydration debate takes a more sanguine view and does not agree that the intention to withdraw nutritional support necessarily entails "aiming at the patient's death," (a perspective adopted by Lutheran theologian, Gilbert Meilaender in his essay, "On Removing Food and Water: Against the Stream," *Hastings Center Report* 14 [December, 1984]: 11-13). Cahill's bibliographic essay is in *Theological Studies* 52 (March, 1991): 107-127. A most helpful taxonomy of the positions in the debate with insightful public policy observations is provided by Michael Place, "The End of Human Life: Ethical and Public Policy Questions," *Chicago Studies* 27 (1988): 257-270.
33. Claremont statement as cited above.
34. Daniel Wikler, "Not Dead, Not Dying? Ethical Categories and Persistent Vegetative State," *Hastings Center Report* (February/March 1988): 41-48, at p. 47.
35. On this score, see the Association for Retarded Citizens of the United States, "Resolution on Cessation of Nutrition and Hydration," and the statement of Disabled People's International (Australia) "Limited, Lives of Inestimable Value: Life Worthy of Life," in *Issues in Law and Medicine*, 7 (Number 2, 1991): at p. 313, and pp. 245-263.
36. Germain Grisez, "Should Nutrition and Hydration Be Provided to Permanently Unconscious and Other Mentally Disabled Persons?" *Issues in Law and Medicine*, 5 (Number 2, 1989): 165-180, at p. 176.
37. Edmund Pincoffs, "Quandary Ethics," *Mind* 80 (1971): 552-571.
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40. William May, et. a., op. cit.
41. Bishops of Washington and Oregon, "Living and Dying Well," op. cit., p. 350.