



Bioethicists Interpret the Papal Speech on Artificial Nutrition and Hydration

In 2003, the Canadian Catholic Bioethics Institute (CCBI) hosted an international colloquium on globalization and the care of the frail elderly and the dying, which was sponsored by the Canadian Association of the Order of Malta. At this colloquium, artificial nutrition and hydration (ANH) was identified as one of the bioethical issues in need of further study and discussion. In June 2004, the CCBI hosted a colloquium on ANH. The context for this colloquium was a speech by Pope John Paul II on March 20, 2004, at a conference in Rome on 'Life-Sustaining Treatments and Vegetative State.' The following account of the Toronto colloquium is based on an interview by Zenit, a Catholic news agency based in Rome, with Dr. William Sullivan, the founding director of CCBI.

What is CCBI's approach to researching bioethical issues?

The mission of the CCBI is to promote and protect the dignity of the human person through interdisciplinary ethics research and education. The CCBI's approach is distinctive in three ways: first, we emphasize integrated, interdisciplinary research. We bring together people with expertise in different areas and with different research skills and functions, for intensive discussions on a particular issue in bioethics. In these discussions, we start by identifying the relevant scientific and moral considerations, and their connections. We also identify areas of agreement and alternative stances in areas where there is disagreement. Second, we try to examine critically the assumptions that lie beneath these alternative stances. Third, we seek to apply the Church's social teachings to bioethical issues.

What was the focus of the Toronto colloquium?

The papal speech addressed the particular case of persistent vegetative state (PVS) or post-coma unresponsiveness. We discussed the implications of the general moral principles that were affirmed and applied in the papal speech to cases of ANH in PVS. We focused on the most common medical conditions affecting the elderly in which ANH is used, such as stroke, Alzheimer Disease, Parkinson Disease, and cancers of the head and neck. Following the CCBI's approach to researching bioethical issues, we considered, first, the clinical differences between PVS or post-coma unresponsiveness and these other conditions, which may be important in assessing the benefits and burdens of ANH. We also discussed an area not addressed by the papal speech, namely, how ought decisions about ANH be made for people who do not have the ability to decide for themselves? Our discussions began with case studies based on the histories of real patients. Second, we discussed some assumptions which seem to underlie disputes about ANH, such as, what constitutes a 'benefit' or a 'burden' of treatment? Third, we considered decisions about ANH in the context of scarce familial and societal resources.

Our colloquium involved thirty participants from Canada, the United States and Australia, whose collective expertise covered the fields of neurology, geriatrics, family medicine, philosophy, theology, pastoral care, clinical ethics, and law. Several participants were invited because they had articulated views on ANH that differed from those of other participants. Commissioned papers were prepared by Joseph Boyle (Toronto), William Sullivan (Toronto), Kevin O'Rourke, O.P. (Chicago), and Nicholas Tonti-Filippini (Melbourne). The

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discussions at the colloquium resulted in a statement, “Reflections on ANH” which is posted on the CCBI website. The statement will also be published, with an introduction, in the Winter 2004 edition of *The National Catholic Bioethics Quarterly*.

What is known about PVS or post-coma unresponsiveness?

Coma occurs after various types of injuries that affect the higher functions of the brain. PVS or post-coma unresponsiveness describes a state in which an individual who was in a coma appears to wake up and to have what are called sleep-wake cycles. The individual, however, remains entirely unaware and unresponsive to the environment. Is there any cognitive-affective activity in the brain? Based on what scientists can observe, they can say that brain metabolism appears to be low in unresponsive patients. They do not know, however, whether this means that there is a global damage to the brain’s neurons or to only some vital brain regions and the connections among them. Science cannot rule out the presence of a spiritual activity in unresponsive patients in whom there is still evidence of some activity in the brain, even though the levels of such activity fall short of those associated with conscious perception. Whether there might be some truth to the Biblical verse, “I am asleep but my heart is awake,” (Song of Songs 5:2) is not a question that falls within the competence of science.

What is meant by ANH?

ANH does not refer only to feeding tubes but also to ways of assisting individuals with a swallowing problem to ingest food and water orally. Trying to feed an unresponsive patient by mouth, however, would be like trying to feed someone who is sleeping. In order to provide such individuals with adequate sustenance safely, one has to find a way to bypass their inability to chew and swallow, and to deliver the appropriate sustenance to their stomach.

What methods of ANH are most commonly used?

If ANH is required for only a short period of time, such as up to one month, it is usually provided by a nasogastric (NG) tube, inserted into the nostril and advanced into the stomach. In the case of an unresponsive patient, it is most likely that a feeding tube will be required for longer than a month, in which case a percutaneous endoscopic gastrostomy (PEG) tube is usually used. A PEG tube is inserted into the stomach through an incision on the surface of the body and the

tube is put in place with the guidance of a flexible gastroscope that is temporarily inserted down the mouth and throat. This procedure takes about 15 – 20 minutes and is carried out under local anesthesia. With nutrition delivered in this way, and with other forms of care, an otherwise healthy unresponsive individual has a life expectancy of between 2 – 5 years. There are even a few well-known cases of young individuals who have continued in post-coma unresponsive states for decades.

Is ANH the same as other life-sustaining technologies, such as dialysis or a respirator?

Some ethicists argue that there is a distinctive social significance attached to nourishing the vulnerable and dependent in our care. This makes ANH importantly different from other medical acts that involve life-sustaining technologies. Giving food and water to those who are hungry and thirsty is a symbolic expression of human solidarity and care giving. For thinkers like Daniel Callahan, the norm of caring for another by providing food and water loses its meaning if ANH is provided to some individuals but not others. On this view, benefits and burdens are not deciding factors.

Other thinkers, however, consider ANH as similar to other forms of life-sustaining technologies. On this view, if ANH is associated with significant burdens for the individual and family in relation to the benefits gained, it may be considered morally optional. Accordingly, ANH needs to be considered in a particular case on the basis of an analysis of the benefits and burdens of this intervention and in light of the patient’s duties. This would be the same as for other interventions like a respirator or dialysis.

What did the papal statement say about ANH for patients in a PVS or post-coma unresponsiveness?

When a patient is being resuscitated, ANH is usually started in a context where doctors are uncertain about the patient’s diagnosis or prognosis. After six or twelve months, depending on the cause of unresponsiveness, the likelihood of recovery becomes increasingly remote. It is in this context that the question of continuing or discontinuing ANH typically arises.

The papal speech states that ANH “should be considered, in principle, ordinary and proportionate and as such morally obligatory insofar as and until it is seen to have attained its proper finality.” Finality refers to the goals of

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“nourishment to the patient and alleviation of his suffering.” So long as these goals can be achieved, ANH should be continued.

How did participants at the Toronto colloquium interpret this statement in the papal speech?

The participants agreed on the following interpretation:

- (1) The papal speech needs to be understood in the context of the Catholic tradition. The words “in principle” do not mean ‘absolute’ in the sense of ‘exceptionless’ but allow consideration of other duties that might apply.
- (2) Persons in a state of lost cognitive and affective capacity retain a spiritual soul; their life has intrinsic value and personal dignity, and they must be treated with the full respect and care owed to a human being.
- (3) For unresponsive patients to whom ANH can be delivered without being in itself in conflict with other grave responsibilities or overly burdensome, costly or otherwise complicated, ANH should be considered ordinary and proportionate, and as such, morally obligatory.

Contrary to some early interpretations presented by the media, the papal speech did not propose that ANH is *always*, i.e. without exception, morally obligatory in patients in a PVS or post-coma unresponsiveness, or in any medical condition for that matter. ANH for an unresponsive patient is “in principle,” or generally, ordinary care, but each case must be assessed separately.

Did colloquium participants think that what the pope said in his speech on ANH and PVS or post-coma unresponsiveness is relevant to elderly people affected by other medical conditions?

Yes, in the sense that the papal speech affirmed the intrinsic value and dignity of all persons. Decisions about ANH ought not be based on the judgment that persons with a severe cognitive and/or physical disability have less value or dignity than other persons. The papal speech also affirmed the distinction between ordinary and extraordinary means of sustaining life. This implies that patients and their family have a responsibility to assess carefully the benefits and burdens of various options for treatment and care, in light of their personal duties. This responsibility is the same with respect to any medical condition and for any patient.

Why did the participants of this colloquium think it was important to address the implications of the Holy Father’s speech for intervening in medical conditions affecting the elderly in which ANH is most commonly used?

One principle of reasoning is that similar cases are to be understood similarly. A second principle is that tough cases make bad laws. That is, rare or unusual conditions are a poor basis for formulating general policies. The participants were aware that, of the cases in which ANH is used in the care of the elderly, normally less than one percent involves someone in a PVS or state of post-coma unresponsiveness. There are many particular and contingent clinical factors that distinguish PVS or post-coma unresponsiveness from other conditions such as stroke, Alzheimer disease, Parkinson disease or cancers of the head and neck. These factors may be relevant to assessing the burdens and benefits of ANH in these conditions.

Can you give examples of how clinical differences might change the assessment of ANH in these conditions?

People affected by a stroke or Parkinson disease are usually conscious, may be capable of swallowing food and fluids with the assistance of others using hand-feeding techniques, and may be capable of consenting to a proposed treatment. In such cases, hand-feeding may be an effective alternative option to tube-feeding. Hand-feeding may also promote a greater sense of solidarity with patients by humanizing their care. People with Alzheimer disease may not understand the reason for a feeding tube and may persist in attempting to pull a tube out, sometimes causing themselves serious injury. A significant burden for such people might be the use of various forms of restraints to prevent them from pulling out their feeding tube. People who have swallowing difficulties because of a cancer of the head or neck may not respond positively to ANH.

For patients with a degenerative neurological condition such as Alzheimer disease, should ANH ever, or always, be offered? If ANH is started, should it ever, or always, be withdrawn at some point?

The colloquium did not seek to prescribe what people ought to conclude in every situation where a decision about ANH for an elderly patient needs to be made. Rather participants wanted to draw attention to some moral principles and to an approach to making decisions about life-sustaining interventions in the Catholic moral tradition that was affirmed in the papal speech. A basic

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guideline for making decisions about any proposed plan of care or treatment, including ANH, is expressed in the statement from the Toronto colloquium: "Treatments cannot be classified ahead of time as ordinary or extraordinary," that is, as morally obligatory or optional (paragraph 7). As mentioned before, a careful assessment must be made of their benefits and burdens in light of the patient's duties.

Alzheimer disease is one of several medical causes of dementia. It is difficult to make general claims about either always or never offering people with dementia ANH because, in the medical literature, there are some limitations to studies showing benefits and burdens. A basic principle of medicine is *primum non nocere* or 'first, do no harm.' If it is evident, in a particular case of advanced dementia, that ANH is, or would be, of little benefit and is, or would, cause significant harm, it may be withheld or withdrawn.

Who should decide whether ANH should be used?

It is the responsibility of the patient and/or the family to make decisions in each case. It is the responsibility of health care professionals, in the appropriate context, to inform the patient and/or the family of the options and the evidence for the benefits and burdens of each option. In doing so, health care professionals are entitled to give a medical opinion.

Did the participants of the colloquium think that advance directives regarding ANH are a good idea?

Yes, the participants thought such directives, if done properly, were a good idea. It is important for persons to anticipate and talk with their loved ones and care givers about end-of-life care before a medical crisis arises. The statement of the Toronto colloquium acknowledges that there may be cultural and jurisdictional variations in the practice of advance directives. In every case, however, a patient who formulates advance directives, the representative of the patient who is authorized to make decisions, and health care professionals who and institutions that, implement these decisions, should always respect the patient's inherent value and dignity.

Your colloquium discussed a number of real-life cases involving ANH for patients with various medical conditions. Was this helpful?

Yes. Beginning with real-life cases ensured that our discussions were relevant to the concrete questions that people face. It also ensured that participants did not neglect particular and contingent factors which may be

relevant to assessing the benefits and burdens of various options. We found that some disagreements that arose when considering principles abstractly turned out not to be morally relevant to the concrete cases.

What topics arose from your colloquium on which Catholic bioethicists need to deliberate further?

There were at least two topics that arose in our discussions. The first issue has to do with whether it is a moral requirement for patients to make decisions about their care in accordance with a deliberate plan for their own lives. A fundamental question here is whether feelings have some role in knowing values, and should be considered in these deliberations. The second issue has to do with how to understand "burden" in treatment. Some confine burden to those of the treatment modality itself, such as pain, suffering or cost. Others also consider the burdens of the underlying illness. One key question here is what is entailed in respecting the dignity of persons who are living with a cognitive and/or physical disability. That is, whether refusing treatment on the grounds of a present or anticipated deterioration in cognitive and/or physical functioning, whether one's own or another's, is compatible with respect for that person's ontological dignity.

Are there any plans underway to address these questions?

Colloquia such as the ones held in Toronto in 2003 and 2004 affirm the fruitfulness of discussions and collaborations among Catholic bioethicists. There is need for similar opportunities for Catholic bioethicists to exchange ideas and to work together nationally and internationally. One recent initiative to promote such ongoing collaboration among Catholic bioethicists around the world is being supported under the aegis of various national associations of the Sovereign Military Order of Malta (see <http://www.iacbweb.org>). It is hoped that a future international colloquium organized in Australia in association with this new group will take up some of the challenging residual questions discussed above.

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