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Reflections on Artificial Nutrition and Hydration Colloquium of the Canadian Catholic Bioethics Institute

Introduction

1. The Canadian Catholic Bioethics Institute sponsored a colloquium in Toronto, June 14-17, 2004. The purpose of this colloquium was to discuss the speech made by Pope John Paul II on March 20, 2004 to participants in the International Congress on 'Life— Sustaining Treatments and Vegetative State' and to assist health care professionals, patients, their families and the community in making decisions about artificial nutrition and hydration (ANH) for elderly patients who have medical conditions other than a 'vegetative state'. Participants in the Toronto colloquium, who work in various fields related to bioethics and had different starting points and perspectives, agreed that the following reflections summarize generally the outcome of their discussions.

Those participants who consented to be listed at the end of these reflections do so in their own name and not on behalf of their institutions. Although all the signatories agreed to the three points of interpretation of the papal speech in paragraph 5, they do not necessarily concur with everything in the reflections.

Presuppositions

2. In keeping with the Catholic moral tradition:

- Life is a gift from God for which we have stewardship. Illness, suffering and death are part of the human condition.
- Humans are relational beings who summon a response from others. All human beings, regardless of their state of health or function, are persons endowed with a spiritual soul and created in the image of God. As such, they possess an intrinsic dignity and value, and have moral status. It follows from this understanding that patients in the state known as 'persistent vegetative state' (PVS) are persons. It also follows that, even when patients with advanced dementia, such as Alzheimer disease, have personalities that are diminished, they remain persons throughout the course of their disease leading to death. Individuals with a developmental or physical disability, even in extreme degrees, also are persons with the same dignity and rights as other persons.

'Vegetative State' (Post-Coma Unresponsiveness)

3. The term 'vegetative state' was developed in reference to certain functions of the autonomic or 'vegetative' nervous system. These functions, such as the regulation of breathing and the heart rate, are retained despite a patient's unawareness of self and environment. Patients in a 'vegetative state' have sleep-wake cycles in which they periodically open their eyes, but they show no evidence of response to the environment, purposeful responses to stimuli and language comprehension or expression. Unfortunately some have misunderstood and misused the term 'vegetative state' to suggest that persons in this state are less than fully human. To avoid this, it is preferable to designate the condition as a state of 'post-coma unresponsiveness'.

4. If post-coma unresponsiveness lasts longer than 6 months following a brain injury from lack of oxygen, or 12 months following a traumatic brain injury, it is conventionally considered to be 'permanent'. This means that the statistical probability of any recovery is minimal but not unprecedented.

The Papal Speech

5. In the responses to the papal speech of March 20, 2004, there have been uncertainty and speculation in regard to the statement 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». The colloquium in Toronto reached the following interpretation of this sentence in the papal speech:

- The papal speech needs to be understood in the context of the Catholic tradition.
  The words «in principle» (n.4) do not mean 'absolute' in the sense of 'exceptionless' but allow consideration of other duties that might apply.
- 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.
- 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.

Is Withdrawing ANH from Post-Coma Unresponsive Patients an Act of Euthanasia?

6. «*Euthanasia in the strict sense* is understood to be an action or omission which of itself and by intention causes death, with the purpose of eliminating all suffering.

'Euthanasia's terms of reference, therefore, are to be found in the intention of the will and in the methods used.'

«Euthanasia must be distinguished from the decision to forego so-called

'aggressive medical treatment', in other words, medical procedures which no longer correspond to the real situation of the patient, either because they are by now disproportionate to any expected results or because they impose an excessive burden on the patient and his family». (*Evangelium vitae*, n. 65)

7. Treatments cannot be classified ahead of time as ordinary or extraordinary. Reference must be made to the wishes1 and values of the patient, his or her condition, and the availability of health care in the given context. Ordinary measures, in the traditional moral sense, do not involve excessive pain, expense or other burdens.2 Extraordinary treatments are those that do involve excessive pain, expense or other burdens. The requirement to undertake an assessment of the benefits and burdens is captured in the alternative designation: proportionate or disproportionate. Some treatments may involve burdens that are disproportionate to the benefits; therefore such treatments are not morally obligatory.

8. The ordinary/extraordinary distinction applies to any stage of illness, not simply to imminent death. However, this distinction may be particularly significant when death is imminent, and the person does not respond positively to treatment. In such circumstances, medical responses other than comfort care and pain control are more likely to be deemed extraordinary and thus optional.

9. While recognizing that it is impossible to place monetary value on human life, the cost of treatment can be a morally relevant factor in health care decisions, especially if patients or their families have to bear the entire economic burden.

10. The increasing technological prolongation of life with its high costs should not eclipse basic human care. This is a matter of fundamental distributive justice.

11. While some treatments may be withheld or withdrawn, care should always be provided, and patients should never be abandoned.

12. Helping patients and their families to make responsible decisions is important. Health care professionals and institutions may be confronted by patients who, with suicidal wishes, refuse ordinary life-sustaining care. Such patients must be treated with concern for their dignity and well-being. Health care professionals should do their

1 Some participants thought that 'wishes' in this sentence should be replaced by 'life plan' or some similar term to indicate that such moral decisions ought not be based on whim but on considerations such as spiritual ends and family obligations.

2 There is considerable controversy over what constitutes burden. Some confine burden to those of the treatment modality itself, such as pain, suffering or cost. Others contend that burden will also encompass the conditions of living after the treatment, including being in a state of diminished or minimal

consciousness, totally dependent on others, incontinent, paralyzed, etc. Some would argue that these conditions are relevant even if the patient is incapable of experiencing them, as in post-coma unconsciousness. A distinction can be made between ontological dignity, which all persons regardless of their level of functioning have, and existential or 'attributed' dignity, which depends on the circumstances or conditions of living. For some, a diminished existential dignity is an insufficient reason for refusing treatment by advance directive. For others, it is a decisive factor in their reasons for not wanting to live in this state. No consensus was reached on this issue. best to protect the life and health of the patient while recognizing that there may be legal and professional limits to their ability to intervene.

Methods of ANH

13. The most commonly used methods of ANH include the following: (a) enteral nutrition and hydration through, for example, a nasogastric (NG) tube that is inserted into a nostril, down the throat and into the stomach or a percutaneous endoscopic gastrostomy (PEG) tube that is inserted through the abdominal wall and placed in the stomach with the guidance of an endoscope that is temporarily inserted through the mouth into the stomach; (b) parenteral techniques which include short-term intravenous (IV) feeding by direct infusion into a peripheral vein such as the arm or leg, and longer-term total parenteral nutrition (TPN), in which complete nutrition and water are delivered directly into a large central vein (such as the subclavian). When a condition warrants temporary nutritional support, very small NG tubes that are more easily and safely inserted than a PEG tube can be used.

Benefits and Risks of ANH

14. While raising many principles of universal applicability, the recent papal speech addressed particularly ANH for people in a state of post-coma unresponsiveness. However, in applying these principles to medical conditions from which the frail elderly are far more likely to suffer, such as Alzheimer disease, Parkinson disease, cancer and stroke, it is important to note that these conditions differ in important ways from post-coma unresponsiveness. The benefits of ANH may include improved nutritional status, the prolongation of life, the symbolic value of giving food and drink, relief of symptoms of hunger when these are experienced, preventing aspiration pneumonia, reducing the risk of pressure sores or infections due to poor nutritional status and immobility, improving function, providing comfort, and maintaining human community. Even in those who have a terminal illness, including patients with advanced dementia, some of these benefits may be attainable.

15. The risks or burdens of ANH include, for NG tubes, irritation and discomfort, and the need for restraint when the patient is confused and

repeatedly pulls the tube out. PEGs carry risks of complications, such as death, infection, perforation of the bowel, temporary diarrhea and cramping, temporary nausea and vomiting, blockage or leaking from the tube. Paradoxically, some patients for whom PEGs are initiated in the hope of reducing their risk of aspiration may still remain at significant risk of aspiration with the feeding tube. This risk is greater when nutrition is supplied to the stomach rather than the small bowel, given in bolus or single and discrete doses, and the patient is lying down when being fed rather than having his or her head elevated. There may be a need for temporary restraints in some confused patients to prevent the tube from being pulled out. Some restraints may constitute an assault on human dignity and autonomy in persons. Restraints can also lead to complications such as pressure sores.

Is ANH Successful in Patients with Advanced Dementia?

16. Randomized controlled trials are the gold standard in research. There appear to be no randomized controlled trials comparing the efficacy of ANH with oral feeding in patients with advanced dementia. However, there is some evidence from less rigorously controlled studies that ANH in these patients does not secure any of the benefits listed above. As it would be difficult ethically to conduct randomized controlled trials with patients suffering from advanced dementia, non-randomized studies and case studies may be the only evidence that we can base clinical practice on.

Others may find these conclusions debatable. In this situation, the health care professional and the patient's family will have to consider the evidence as best they can. The health care professional is entitled to give an opinion as to the most beneficial and least burdensome type of ANH and course of action.

Advance Directives

17. Advance directives, whether in the form of a written living will (instructional directive) or a durable power of attorney for health care (proxy directive) or both together, are legitimate instruments by which patients may indicate their wishes to accept or refuse a procedure when they are no longer capable of making the decision.

Acceptable purposes include:

- To lighten the burden of a patient's family in making the decision;
- To ensure that future treatment is morally acceptable and consistent with respect for human life and dignity, and the patient's values and culture;
- To take into consideration responsible stewardship of society's health resources;
- To prevent inappropriate or disproportionate treatment.

18. An advance instructional directive must reflect the duty to respect human life and dignity and to continue ordinary/proportionate measures.

19. An advance directive must not require another to cooperate in a plan of care that is morally unacceptable to that other person.

20. A Catholic health care professional or institution should not cooperate in implementing a suicidal directive.

21. The requirement of an advance directive by a nursing home or long-term care facility as a condition of admission may be unacceptably coercive. In many cultures, advance directives are not valued, and end-of-life decisions for incompetent patients may be left to family members.

22. For a patient, appointing someone to represent him or her is preferable to issuing an instructional directive, but the representative must be well-instructed in the patient's wishes and values.

23. A person who is a representative of a patient has the same rights and responsibilities as the patient to respect and protect the patient's life and dignity and to authorize care.

24. A health care professional or other caregiver must respect the rights and responsibilities of the representative of an incompetent patient and discuss with the representative the care that is appropriate.

25. A health care professional or other caregiver must seek review of the representation in the event that the representative fails to act in the best interests of the patient, and the patient is endangered.

26. Health care professionals and families need to be aware of jurisdictional differences, in custom and law, relevant to advance directives.

List of Signatories

Joseph Boyle Toronto, Canada
Barry Brown Toronto, Canada
Eoin Connolly Toronto, Canada
Michael Coughlin Hamilton, Canada
Paola Diadori Montréal, Canada
Rory Fisher Toronto, Canada
John Heng London, Canada
Christine Jamieson Montréal, Canada
Nuala Kenny, sc Halifax, Canada
Hazel Markwell Toronto, Canada
Moira McQueen Toronto, Canada
Pat Murphy Winnipeg, Canada
Patricia Murphy Toronto, Canada
Fr. Robert O'Brien Toronto, Canada
Fr. Kevin O'Rourke, op Chicago, U.S.A.
John Shea Toronto, Canada
Fr. Noël Simard Ottawa, Canada
William Sullivan Toronto, Canada
Daniel Sulmasy, ofm New York, U.S.A.
Beverly Tezak Toronto, Canada
Nicholas Tonti-Filippini Melbourne, Australia
Michael Vertin Toronto, Canada
Marissa Zorzitto Toronto, Canada
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For more information:

Canadian Catholic Bioethics Institute, 81 St. Mary's Street, Toronto, Ontario, Canada M5S 1J4. Telephone: (1) 416-926-2335 E-Mail: bioethics.usmc@utoronto.ca To obtain background papers: www.utoronto.ca/stmikes/bioethics