

Distinguishing ethically suitable and culpable decisions to forgo life-prolonging treatment: the role of medical information

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INTRODUCTION

The focus of this paper is on the role of medical information in helping health care providers and persons who are incurably ill and dying to make responsible decisions about withholding, withdrawing or refusing life-prolonging treatment. Such decisions are different morally from decisions for suicide or euthanasia, in which the death of the patient is not only foreseen but also intended, and in which the patient's intrinsic value and stewardship of life is not respected. In the first part of the paper, drawing upon Maurizio Calipari's recent work, I will highlight the dialogical nature of the relationship between health care providers and patients, and their distinct but mutually supportive roles and responsibilities in deciding upon the overall goal of care and treatments. In the second part of the paper, I will illustrate with case examples various issues pertaining to the usefulness and limitations of medical information in distinguishing between ethically suitable and culpable non-treatment decisions. I will conclude with some comments on what responsible stewardship of a person's life might entail in the contemporary world situation in which the prevalence of incurable life-shortening diseases continues steadily to rise.

TERMINOLOGY

Because there sometimes is confusion about the difference between morally acceptable decisions to forgo life-prolonging treatments and those that are unacceptable

and may involve euthanasia or suicide, I will begin with some considerations regarding terminology.

Anthony Fisher has written that “medical abandonment and killing by deliberate neglect, sanctioned by gradual erosion of the common law and gradual change in medical practice, is the most likely way for euthanasia to become widespread.”¹ This seems to be confirmed by a recent survey based on EURELD, a large research project on end-of-life care in six European countries, which suggests that about half of all medical decisions of physicians to withhold or to withdraw treatment of dying persons were made with the specific intention of hastening death.²

The Catholic position is clear: all forms of euthanasia that “of itself and by intention causes death, with the purpose of eliminating all suffering” are wrong.³ Withholding or withdrawing a life-prolonging treatment with the deliberate intention of causing the death of the patient is euthanasia, and refusing such treatment with the intention of causing one’s own death is suicide.

Using the terms “passive” or “omissive” euthanasia to describe such cases, however, is confusing and should be avoided for several reasons.⁴ First, the “omission” that results in the intended death of the person often involves an *action* such as removing a respirator or a feeding tube.

¹ FISHER A., *Theological aspects of euthanasia*, in KEOWN J. (ed.), *Euthanasia examined: ethical, clinical and legal perspectives*, Cambridge: Cambridge University Press, 1995: 315-332 at 322.

² BOSSHARD G., FISCHER S., VAN DER HEIDE A., MICCINESI G., FAISST K., *Intentionally hastening death by withholding or withdrawing treatment*, Wiener Klinischer Wochenschrift 2006, 118(11012): 322-6.

³ EVANGELIUM VITAE, no. 65.

⁴ INTERNATIONAL COLLOQUIUM, *Globalization and the culture of life consensus statement*, National Catholic Bioethics Quarterly 2004, 4(1): 142.

Second, and more importantly, not every decision to forgo life-prolonging treatment is euthanasia or suicide. *Evangelium vitae*, quoting the 1980 Declaration of the Congregation for the Doctrine of the Faith on Euthanasia, states that:

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....To forego extraordinary or disproportionate means is not the equivalent of suicide or euthanasia; it rather expresses acceptance of the human condition in the face of death.⁵

As John Haas has pointed out in his paper, perhaps a better translation from Latin of “aggressive” in the quoted passage in *Evangelium vitae* is “excessive”.⁶ The failure to distinguish appropriately between so-called “passive” or “omissive” euthanasia and morally acceptable decisions to forgo life-prolonging treatment, on the grounds that it is “excessive”, has led some people to adopt, mistakenly, the vitalist position that insists on using every available means to prolong life without considering the circumstances of the person who is dying and the reasonable benefits or burdens of treatment for that person and his or her loved ones. On the other extreme, many think that they have to support euthanasia and assisted suicide as the counterweight to the vitalist position that may push people into medical situations that become impossible for them to bear.

A similar ambiguity obscures the term “allowing to die” in the bioethics literature. What does intending to “cause” death mean in the context of a person who has an incurable life-shortening disease? Some have argued that, in such a context, the disease and its complications cause death, and that the forgoing of life-prolonging treatment follows from a decision not to extend or delay the dying process. Hence it is claimed that

⁵ EVANGELIUM VITAE, no. 65.

⁶ This is an important terminological difference since one could reasonably categorize certain treatments as “aggressive” apart from any reference to the condition of a particular person who is ill, whereas “excessive” treatment would seem to be deemed so in relation to that person’s circumstances.

by withholding, withdrawing or refusing treatment, the person is “simply” allowed to die. A further specification, I think, is needed to differentiate between two types of allowing to die.⁷

In Catholic moral reasoning, the intention of the person who is deciding to forgo life-prolonging treatment is crucial.⁸ In some instances of “allowing to die”, the death of the person who is ill is both *foreseen and intended*, for instance, by forgoing life-prolonging treatment, not because it is judged to be excessive, but in order to end the life of the patient because his or her life is “no longer ‘worth living’ or that it no longer has value or dignity”. Actions or omissions of this sort are always wrong.⁹ In other cases of “allowing to die” by forgoing life-prolonging treatment, the death of the person who has an incurable illness is foreseen as likely on account of the frailty of his or her overall condition, but causing his or her death is not intended. The judgment here is that there no longer is any compelling moral reason for the patient to prolong life or delay death, whereas there are likely to be, or are, significant burdens for the patient and his or her loved ones associated with initiating or continuing a life-prolonging treatment. In the Christian understanding, a person has a moral responsibility for stewardship of his or her life as a gift from God and for service to others, but the ultimate good of a human life is not longevity.

In this paper I am using the expression “ethically suitable forgoing of life-prolonging treatment” to distinguish this from other instances of “allowing to die” in

⁷ For a good discussion of this point, see SULLIVAN W.F., *Killing and allowing to die: another look*, *The Journal of Law, Medicine and Ethics* 1998, 26(1): 55-64.

⁸ For a philosophical defence of this position, see SULLIVAN W.F., *Eye of the heart: knowing the human good in the euthanasia debate*, Toronto: University of Toronto Press, 2005.

⁹ *Colloquium of the International Association of Catholic Bioethicists (IACB): Consensus Statement*. In MONSOUR H.D., SULLIVAN W.F., HENG, J. Eds. *Dignity in illness, disability, and dying: proceedings of the second international colloquium of Catholic bioethicists, Melbourne, Australia, June 26-30, 2005*. Toronto: IACB, 2007, p. 134.

which withholding, withdrawing or refusing such treatment constitutes what Anthony Fisher called “medical abandonment” or “deliberate neglect” of a person who is ill and dying. I begin with the presumption that euthanasia and assisted suicide are always wrong, that some instances of withholding, withdrawing or refusing life-prolonging treatment may be euthanasia or suicide, and that one can discern whether this is the case by the circumstances and by the intention of the decision maker(s) involved. But I recognize also that much work needs to be done in elaborating on the Church’s tradition of reasoning about forgoing life-prolonging treatments to make it practical for health care providers and persons who are dying, or their substitute decision makers, to apply. This work in ethics and in medicine is necessary to enable individuals to make informed and responsible decisions in light of their responsibilities for stewardship of life as God’s gift and for service to the community as an essential aspect of their friendship with God. Promoting informed and responsible decision making is an important way in which ethicists can be “close to the incurably ill and the dying”.

MEDICAL DECISION MAKING

Two contemporary trends in health care have shaped prevailing views on giving or refusing consent for treatment. The mechanization of health care tends to reduce patients to a set of measurements taken by means of machines or of scores on standardized tests or scales. Some hold the position that decisions about care should be based only on such “objective” or “value neutral” facts. In contrast, there has also been a trend towards advancing an uncritical form of patient autonomy in health care that accepts a person’s merely “subjective” preferences and wishes as goods for that person

without need for further discussion or justification to others. Both trends presuppose an unbridgeable chasm between an objective world independent of particular persons and a subjective world that is the private realm of individuals, and they privilege one or the other as the basis of decisions regarding health care. A fundamental necessity in ethics today is to examine the adequacy of this bifurcation.¹⁰

The Canadian thinker Bernard Lonergan has proposed that objectivity in any kind of knowing and deciding is “the fruit of authentic subjectivity”.¹¹ This entails that any philosophically adequate account of decisions about health care should recognize both the contribution of personal factors in judging facts as well as values, and that such judgments can be affirmed or denied as reasonable and responsible by some broader standard than just that of the decision maker himself or herself. “Authentic subjectivity” refers to the quality of a person’s performance in knowing, whether he or she is inquisitive, attentive, intelligent, reasonable, and responsible in his or her acts of knowing and deciding. The more skilled the person is at knowing and deciding, the more likely it is that this person will discover what is realistic and genuinely worthwhile to enjoy or to pursue in his or her concrete circumstances.

According to Lonergan, knowing and deciding involve a dynamic process that is animated by questioning and wonder, and it involves four distinct sets of activities that follow a natural sequence: the first is *experiencing* or attending to data; the second is *understanding* or discovering intelligible patterns in data; the third is *judging fact* or checking our understanding and weighing the sufficiency of evidence for it; the fourth is

¹⁰ For an elaboration on this point and its importance in teaching ethics in medicine, see SULLIVAN W.F., HENG J., *Moral education in health care professionals*, in LIPTAY JR., J.J., LIPTAY D.S. (eds.), *The importance of insight: essays in honour of Michael Vertin*, Toronto: University of Toronto Press, 2007: 172-182.

¹¹ LONERGAN B., *Method in theology*, New York: Herder and Herder, 1972: 55.

judging value or considering the worthwhileness of what our judgment of fact brings to light, and deciding to enjoy or to pursue it. The process of knowing and deciding is self-correcting in that, as new questions or data or understandings arise, judgments of fact and of value and decisions can be revised. This continual process of trying to get things right involves both personal effort and care as well as cooperation with people who might hold other relevant pieces of the puzzle.

In medical decision making this process is *dialogical* and the cooperation of the health care provider and the patient is crucial to determining the overall goal of care and ethically suitable treatments. Each goes through the four steps of decision making outlined above, and each relies on and trusts the other to perform his or her steps adequately. For the health care provider, the first step of exploring relevant data involves not only obtaining information *about* the patient through observations and measurements but also *from* the patient or from an incapable person's substitute decision maker in doing a thorough physical, psychological, social, and spiritual assessment,¹² to discuss the overall goal of care appropriate for that patient in his or her particular circumstances. The overall goal of care would depend on the response, or presumed response, of the person to the question, what do I hope for before dying? What remains to be enjoyed or achieved to enable the person with a life-shortening illness to die in the manner of Simeon who prayed, "Master, now you are dismissing your servant in peace"?¹³

Overall goals of care at the end of life tend to emphasize the priorities of prolonging life, maintaining functions, or maximizing comfort, although these goals may

¹² For a good review of issues concerning spiritual assessment, see PUCHALSKI C.M., *Spiritual care: practical tools*, in PUCHALSKI C.M. (ed.), *A time for listening and caring*, Oxford: Oxford University Press, 2006: 220-251.

¹³ *Luke 2:29*.

be in tension or conflict in a given case. The goal of prolonging life places the emphasis of the patient on treatments that could extend survival even if these treatments are, or are likely to be, burdensome for the patient and his or her loved ones. The goal of maximizing comfort prioritizes palliative care measures and sometimes entails forgoing burdensome or potentially burdensome treatments even if they could extend survival. The goal of maintaining functions lies between these two goals and may be pursued through low-risk, minimally invasive but potentially effective treatments for particular life-threatening events as they arise, such as the use of antibiotics and intravenous fluids for pneumonia.¹⁴ The patient or substitute decision maker, following a discussion with the health care provider, can be assisted to formulate an overall goal of care that is medically and ethically suitable for the patient's circumstances that both should agree upon. Such goals should be in keeping with respect for the equal intrinsic dignity of all human beings and with the restorative or supportive aims of medicine. These goals should address the patient's moral obligations to self and others, including their spiritual discernment regarding these obligations. This is why in formulating such goals, health care providers and patients should also be open to the spiritual aspect of human beings, what Edmund Pellegrino and David Thomasma have called the patient's "ultimate good", which for the Christian is friendship with God.¹⁵ Goals of care may change over the course of a person's illness. Therefore an ongoing dialogue between the health care provider and patient or substitute decision maker, regarding goal of care, is necessary and

¹⁴ GILLICK M.R., *Choosing appropriate medical care for the elderly*, Journal of the American Medical Directors' Association 2001, 2(6): 305-309.

¹⁵ PELLEGRINO E.D., THOMASMA D.C., *For the patient's good: the restoration of beneficence in health care*, New York: Oxford University Press, 1988.

will be crucial to making decisions regarding withholding, withdrawing or refusing life-prolonging treatments.

In relation to an agreed-upon overall goal of care, the patient or substitute decision maker relies on the health care provider to propose, explain, and discuss his or her ranking of reasonable and available options for care as part of the data that he or she must consider to provide informed consent. Such medical information not only relates to judgments of fact made by the health care provider but *also judgments of value* because the health care provider is conveying one or more options, including possible non-treatment, that he or she deems to be medically *worthwhile and ethically suitable* to pursue given the agreed upon overall goal of care. Similarly, the patient or substitute decision maker must make both a judgment of fact about the comparative benefits and burdens *for the patient* of various proposed treatments, and also a judgment of value, after deliberating carefully on the person's moral obligations, regarding whether or not it is worthwhile to undertake such treatments in pursuit of the overall goal of care.

It strikes me that such an account of medical decision making as a dynamic and cooperative process is helpfully supplemented by the recent work of Maurizio Calipari concerning the Catholic tradition of moral reasoning about proportionate and extraordinary means of prolonging life.¹⁶ Calipari proposes distinguishing and relating two different elements in any decision regarding life-prolonging treatments: the judgment that a treatment is proportionate or disproportionate to a given overall goal of care primarily in terms of its overall benefit to the patient, and the judgment that it is ordinary or extraordinary for that person, primarily in terms of its burdens to the patient and his or

¹⁶ CALIPARI M., *Curarsi e farsi curare: tra abbandono del paziente e accanimento terapeutico*, Milan: Edizioni San Paolo, 2006.

her community. The first is a judgment concerning the technical and medical adequacy of using a given means (*adeguatezza o inadeguatezza “technico-medica” del suo uso*) to attain the overall goal of care agreed upon by the health care provider and the patient. This includes both carefully considering the medical efficacy (*efficacia medica*) of treatments for specific health targets as well as their “global efficacy” (*efficacia globale*) or the real difference these treatments would make on the overall condition of the particular patient and his or her circumstances. Judgments of proportionality therefore include person-specific considerations such as the extent and manner of access to treatment, risks of harm given the person’s particular vulnerabilities, and the comparative medical suitability of alternative treatments for that person.¹⁷

The second distinction is between the ordinariness or extraordinariness of treatments deemed to be proportionate in the sense above. Calipari proposes that life-prolonging treatments are “ordinary” (i.e., responsible stewardship of life presumes their use in principle) unless the patient would experience, or until he or she does experience in the situation “some impossibility” (*quaedam impossibilitas*) in its use. Calipari interprets this criterion of “impossibility” in terms of the excessive effort or intractable pain or economic burden or severe fear or repugnance that would be, or is, associated with the treatment by the patient, his or her unwillingness to tolerate the adverse effects or the risk of such adversities from the treatment, as well as considerations of justice and charity that bear on that person’s decision not to undergo treatment.¹⁸

In my view, what Calipari has helpfully clarified is that the “excessiveness” of treatments involves *two distinct considerations* and *requires two distinct judgments*. First,

¹⁷ *Ibid.*, pp. 152-157.

¹⁸ *Ibid.*, pp. 157-163.

a given treatment might be judged “too much” therapy in relation to the overall goal of care for the patient. For example, radiosurgery to try to shrink a brain tumour might be judged by a patient to be “excessive” if the patient’s overall goal of care is maximizing comfort, in the sense described above, but might not be so judged if the goal is to maintain cognitive functions such as lucidity. Second, a treatment might be judged to be “too much” in relation to the psychosocial burdens involved in the treatment for the patient and his or her community.

Furthermore, the tradition of ordinary/extraordinary means in Catholic moral reasoning has allowed considerations of reasonable hope of benefit and of the burdens of treatment without specifying *in what order* these are to be addressed. In proposing that judgments regarding benefit in terms of the overall goal of care for the patient (taking into account the likelihood of adverse medical side effects) methodologically precede those regarding psychosocial or economic burden, even if in the end, both judgments are integrated into a single decision about whether or not to proceed with or to continue a life-prolonging treatment, Calipari has helpfully distinguished between the respective roles and responsibilities of health care providers and of patients in cooperating to make such decisions.

At this point, two further clarifications need to be made regarding notions of patient autonomy and the “futility” of treatments, concepts that are often used in medicine and in ethics.

First, I think it is important to highlight that the “dialogical” or cooperative model of medical decision making that I have drawn from the work of Lonergan and Calipari avoids the excesses of either considering patient autonomy as the only relevant

determinant in medical decision making or of paternalism in health care providers, in which they do not duly recognize the patient's legitimate responsibility to participate in medical decision making. Regarding the former tendency, Eric Cassell has recently written:

Thirty-five or forty years ago, it was acceptable to pretend that context, illness, and other people, benevolent or otherwise, had no impact on autonomy. Or that there are such things as totally independent choices. These ideas...arise from a view of the human condition as made up of atomistic individuals spinning in their own orbits among others doing the same, and they are just as wrong as the positivist model of science and atomistic facts on which they are probably based. Now the task is to develop an understanding of persons and their relationships that can form a solid intellectual and theoretical basis for contemporary and future ethics.¹⁹

As part of the dialogical nature of medical decision making, it is in keeping with the health care provider's roles and responsibilities to go beyond merely listing for patients or their substitute decision makers various options for treatment and then asking them to go away and return with a decision. Rather, health care providers should ensure that patients or their substitute decision makers understand the options and appreciate the implications of each for themselves and their communities. Health care providers should also contribute to the deliberative process by making non-coercive recommendations regarding the medical ranking of the various life-prolonging treatment options in light of the agreed upon overall goal of care for the patient. The sharing of this sort of value-judgment by health care providers with patients or their substitute decision makers would normally be in keeping with their professional expertise.

"Futility" is a controversial concept that is used by health care providers and ethicists, although there is no universal agreement on its meaning. The reality is that

¹⁹ CASSELL E.J., *Unanswered questions: bioethics and human relationships*, Hastings Center Report 2007, 37: 20-23, on p. 21.

health care providers sometimes do not propose or accept particular requests for treatment that they judge to be “futile” for the patient. This is problematic ethically if futility is understood too broadly by the health care provider to encompass even those judgments that, according to my analysis above, are not exclusively within the competence of the health care provider to make and would require the input of the patient or substitute decision maker. On the other side of the issue, patients or their loved ones sometimes insist on treatments that health care providers may legitimately judge to be unreasonable and unrealistic. In addressing these ethical concerns, Calipari’s interpretation of the Church’s teaching on ordinary/extraordinary means could, I suggest, be developed by a further distinction between value-judgments regarding “futility” and value-judgments regarding the “proportionality” and “ordinariness” of treatments.

Bernard Lo has proposed that “futility” be understood in a precise way to indicate that a given treatment simply is not a worthwhile option to pursue for a patient for at least one of four reasons: (1) The treatment is irrelevant to the patient’s real condition in the sense that it has no pathophysiologic rationale; for example, cancer chemotherapy for a patient’s infectious lung condition; (2) maximal treatment is already failing, such as when multi-organ failure is still occurring when a patient is ventilated, undergoing pressure support, dialysis, and a number of other interventions in the Intensive Care Unit; (3) an identical treatment has already failed in the same patient despite best efforts to provide it; for example, re-running a resuscitation code when a previous unsuccessful attempt or attempts have been made following established protocols; (4) according to the best available evidence, the treatment is ineffective in achieving the overall goal of care as

identified by the patient or substitute decision maker.²⁰ It is my view that judgments about the futility of treatments, understood in this strict sense, are judgments of fact and of value that are within the competence normally of health care providers to make, and health care providers would be ethically justified neither to propose such measures to patients or substitute decision makers nor to support them if requested. It goes without saying, however, that in health care, as much effort as possible should be made to ensure that patients or substitute decision makers have access to a second opinion if they have questions about the professional competence of their particular health care provider.

The judgment of “proportionality”, I maintain, is a separate category of judgment. It pertains to those judgments that are necessary when medical information regarding the effectiveness of possible treatments in relation to the agreed upon overall goal of care is probable or incomplete. Medical information regarding prognosis and treatment outcomes is based on data from individual case studies or drawn from the health care provider’s experience with patients with similar health conditions or statistical studies involving comparable groups of patients. Sometimes there may be “evidence based” consensus guidelines that have been formulated regarding the diagnosis, prognosis, and treatment of particular illnesses. There may nevertheless often be some uncertainty associated with such medical information for various reasons, including some of the following:

First, as Lonergan has pointed out, statistical inquiry is concerned with nonsystematic processes, and there may be occurrences in an individual that diverge from

²⁰ LO B., *Resolving ethical dilemmas: a guide for clinicians*, Baltimore, Williams and Wilkins, 1995.

the norm of the studied population.²¹ Some of this variance is due to chance and some to various factors or interactions among factors that might be significant to the course of an illness or the outcome of a treatment in a particular patient. Second, the strength of evidence of research studies is affected by factors such as limits on the capacity or time or availability of ethical means to undertake certain investigations.

The fact that medical information is probable or incomplete does not entail that a judgment regarding the proportionality of treatments to the agreed upon goal of care can never be made with some degree of confidence. But it should be acknowledged that such judgments are always, in principle, open to revision as new questions, data, and understandings emerge, and that the patient or substitute decision maker should be informed about options that are consistent with the overall goal of care for that patient even if the probability of the treatment's effectiveness for that goal is very low for similar patients, but greater than zero, and the health care provider would normally recommend against it. In other words, unlike judgments regarding futile treatments, understood in the strict sense outlined above, judgments regarding the proportionality of treatments to the agreed upon overall goal of care should be discussed with the patient or his or her substitute decision maker.

For a health care provider, a crucial component of "being close" to the incurably ill and the dying is by being competent and responsible in making the judgments of fact and value that are necessary so that patients can make reasonable and responsible decisions regarding care, including those involving withholding, withdrawing or refusing life-prolonging treatments. This brings me to the next part of my paper in which I will

²¹ LONERGAN B., *Insight: a study of human understanding*, 5th revised and augmented edition, Toronto: University of Toronto, 1992, p. 79.

consider in greater detail, through case illustrations, how medical information could serve to distinguish ethically suitable forgoing of life-prolonging treatment from morally culpable non-treatment.

CULPABLE NON-TREATMENT DECISIONS

From the analysis above, it can be inferred that ethically suitable decisions regarding withholding, withdrawing or refusing life-prolonging treatments will not involve intending the death of the patient (even if his or her death can be foreseen) but forgoing treatment that is judged by the health care provider, in consultation with the patient or substitute decision maker, to be “disproportionate”, or if judged to be “proportionate” by the health care provider, the patient or substitute decision maker, in consultation with the health care provider, judges it to be “extraordinary”. There are, therefore, three ethically relevant considerations for such decisions: (1) the right intention, (2) the observance of the proper roles of both health care provider and patient (or substitute decision maker), and (3) the authenticity of the fact and value judgments involved.

It is beyond the role and responsibility of the health care provider at any time unilaterally to decide on the overall goal of care for a capable patient, without consulting the patient, or consulting a substitute decision maker, if the patient is not capable. If there is no agreement on the overall goal of care, and this conflict cannot be resolved through such means as an ethics consultation or pastoral or psychological counseling, then the health care provider should transfer the care of this patient to another health care provider.

The health care provider could in good conscience decide not to discuss treatment options that the medical community generally would deem to be medically futile, in the strict meaning of this term outlined above, for the agreed upon overall goal of care in patients with this condition. However, the health care provider *would* be morally culpable if he or she were intentionally to withhold information from a patient or substitute decision maker regarding “proportionate” treatments that the patient would likely judge, or could be presumed to have judged, to be “ordinary” (i.e., not excessively burdensome).

With respect to a capable patient or an incapable patient who has provided a clear and relevant advance directive while capable, it is morally acceptable to forgo a “proportionate” treatment proposed by the health care provider on the grounds that it is or would be “extraordinary” and therefore optional. However, if a patient were to reject a treatment that is both “proportionate” and that reasonable persons would normally judge to be “ordinary” for persons in similar circumstances, the reason(s) for this decision should be explored. That patient would be morally culpable if he or she were acting with a suicidal intention.

With respect to a substitute decision maker of a patient who has provided a clear and relevant advance directive while capable, it would normally be morally acceptable to follow the patient’s expressed wish to decline a proportionate treatment in such anticipated circumstances because it would be “extraordinary” and therefore optional. Conversely, the substitute decision maker would be morally culpable if he or she deliberately declined, on the patient’s behalf, a treatment that the patient had judged would be “ordinary”, if “proportionate” to the desired level of care in a given

circumstance. The substitute decision maker would also be culpable if he or she deliberately followed a suicidal advance directive declining all “ordinary” measures on behalf of the patient.

If a patient had never been capable, or had become incapable and had never provided a clear and relevant advance directive, it would normally be morally acceptable for the substitute decision maker to decline a “disproportionate” treatment. However, if the substitute decision maker were deliberately to decline, on the patient’s behalf, a “proportionate” treatment that reasonable persons would normally regard as “ordinary”, the reason(s) for this decision should be explored. The substitute decision maker would be morally culpable if he or she intended the patient’s death because he or she judged the patient’s life to be of “no value” or “little value”, or for secondary gain, such as to benefit from an inheritance.

I will illustrate these points with concrete cases and highlight both how medical information can be relevant to distinguishing between morally acceptable decisions not to treat and those that are morally questionable or unacceptable and also some areas of uncertainty that may not be settled by appeals to the relevant medical information. It should be noted, however, that there might be relevant medical information in a particular “real-life” situation that could change the ethical analysis presented in the following cases.

ILLUSTRATIVE CASES

Case #1: Advanced Dementia

In the *Journal of the American Medical Association*, physician Susan Mitchell discusses the case of Mr. P., a 93-year-old man with advanced dementia and eating problems.²² In addition, Mr. P. has type-2 diabetes mellitus, hypertension, chronic renal insufficiency, possibly renal cell cancer, benign prostatic hypertrophy, a tendency to fall, and behavioural problems. He also had episodes of unresponsiveness, which were associated with dementia-related encephalopathy. His problem behaviours included agitation, aggression toward others and refusing to eat. After a swallowing evaluation was performed, changes were made to the consistency of his food and liquids to make them easier to swallow, his dentures were refitted to make them more comfortable when chewing food, and medications were given to correct his constipation. As a result, his oral intake improved. A few months later, however, Mr. P. fractured his hip from a fall and, after surgery, again refused to eat or drink. He was provided with intravenous fluids for several days, but his oral intake with hand feeding did not improve, and he eventually pulled out the intravenous catheter. This last development raised questions regarding whether or not to initiate tube feeding (artificial nutrition and hydration or ANH) to improve Mr. P.'s nutritional status. While capable, he had neither completed an advance directive nor expressed his wishes regarding this situation to his daughter, who is acting as his substitute decision maker.

How might medical information be relevant and helpful for determining a suitable overall goal of care in this circumstance for Mr. P. and judging the “proportionality” of possible options of care for him given this goal?

²² MITCHELL S., *A 93-year-old man with dementia and eating problems*, JAMA 2007, 298(21): 2527-2536.

At the outset, it is important to be clear about the natural history and course of the underlying illness and co-morbid conditions experienced by Mr. P. Aside from the life-threatening implication of Mr. P.'s refusal to eat or be fed, is Mr. P. dying?

Mr. P.'s dementia could be due to Alzheimer's disease or to some other medical condition. The etiology of his dementia is relevant because different etiologies are associated with different prognoses. For instance, vascular dementia normally results in deterioration of the patient after a stroke but the patient's function may not continue to decline and may even improve if no further strokes occur. Alzheimer's disease, however, is a terminal illness. ANH is less likely to be judged "proportionate" to the goal of improving survival for patients with a disorder that is progressing towards death than for one whose medical condition is stable and may improve.

Alzheimer's disease is also different in medically relevant ways from post-coma unresponsiveness (PCU) or a "permanent vegetative state" (PVS), for which ANH would in principle be regarded as ordinary care.²³ Assuming that Mr. P.'s dementia is due to Alzheimer's disease, and given that he has several co-morbid conditions, some of which are lethal, he is progressing towards death regardless of ANH or other possible treatments. This is unlike the relatively stable medical condition that typically characterizes persons with PCU receiving ANH. In addition, Mr. P. can ingest some food and fluids orally by hand feeding, at least to the extent that he is willing to accept them, unlike persons with PCU.

²³ JOHN PAUL II, *Address to the participants in the international congress on "Life-sustaining treatments and vegetative state: scientific advances and ethical dilemmas"*, March 20, 2004, n. 4. See also CONGREGATION FOR THE DOCTRINE OF FAITH, *Responses to certain questions of the United States Conference of Catholic Bishops concerning artificial nutrition and hydration*, August 1, 2007, the accompanying *Commentary* to this document, and *Reflections on Artificial Nutrition and Hydration: Colloquium of the Canadian Catholic Bioethics Institute*, National Catholic Bioethics Quarterly 2004, 4:773-82.

In her commentary on the case, Susan Mitchell reports that the best available studies suggest that there is little evidence supporting any purported benefits of ANH in persons with advanced dementia for improving nutritional status or preventing pneumonia resulting from aspiration. In addition, she reports that there is a small to moderate risk of problems such as bowel perforation, tube dislodgement, tube blockage, and tube leakage due to technical problems or to patients attempting to remove tubes. Some of these complications could be life-threatening and might result in requiring either the use of physical or chemical restraints or to transferring the person to an acute care facility. Mitchell reports that the expert medical opinion, based on such considerations, is that hand feeding should be the default for patients with advanced dementia, and that tube feeding should not be offered. In Mitchell's own practice, she does not "introduce the option of tube feeding for a patient with advanced dementia, unless the health care proxy specifically brings it up as a possibility", in which case, she is "prepared to counsel the family through the decision-making process".²⁴

In Mr. P.'s case, however, the medical evidence does not necessarily point to ANH as futile (i.e., physiologically useless or irrelevant to addressing the condition of the patient) in all cases of persons with advanced dementia because the empirical studies regarding benefits for survival are based on limited data.²⁵ Taking these limitations into

²⁴ MITCHELL, *A 93-year-old man...*, p. 2531.

²⁵ First, the established gold-standard of evidence supporting any empirical claim is a randomized controlled trial. Such studies have never been conducted regarding the benefits of tube feeding for persons with advanced dementia and are unlikely to be done due to the ethical difficulties that they would pose. The best available empirical evidence to assess the purported benefits of ANH in advanced dementia is from observational studies that follow case-controlled or matched groups of persons with advanced dementia, some of whom received tube feeding and others who did not. Such studies are limited by selection bias related to uncontrolled for and possibly significant differences between the groups studied, for instance, increased human contact in those receiving hand feeding. Another limitation in the available medical information is the challenge of predicting the life expectancy of anyone with dementia based on

consideration, it might still be the health care provider's competent judgment that hand feeding or intravenous feeding should be attempted first. That is, they rank more highly as proportionate treatments for the overall goals of improving nutrition and likely survival while providing comfort. However in Mr. P.'s situation, these modes of feeding have been tried and were unsuccessful, and ANH now seems to be the highest ranking treatment option for this overall goal of care. ANH could be considered "proportionate" treatment in this case since, relative to alternative treatments and non-treatment, it is likely to be more beneficial, and such benefits are not likely to be reversed by any significant risk of severe adverse effects.

The health care provider should at least discuss the option of tube feeding with Mr. P.'s daughter in the latter context. Not to do so would be to overstep the role of the health care provider. If the agreed upon overall goal of care is prolonging Mr. P.'s life through "proportionate" and "ordinary" means, because this is what Mr. P. clearly would have wanted and because he would not have judged such treatment to be excessively burdensome, then in light of the failure of the other higher ranking options for feeding, ANH should be tried to see if it would be effective in improving nutrition and would, in fact, be tolerated by Mr. P. However, if there is uncertainty about what Mr. P., who will die soon even if his feeding problem is addressed, would have wanted in these circumstances, or if there is evidence that Mr. P. finds tube feeding distressing, the health care provider could discuss with Mr. P.'s daughter the possibility of moving to an overall goal of palliation for Mr. P. This would likely involve forgoing tube feeding if there is

the typical functional staging criteria and hence determining whether there has been a statistically significant improvement of survival in persons with advanced dementia who receive ANH.

no evident discomfort caused by non-feeding that could not be addressed by optimal nursing care.

To illustrate the shift from the health care provider's assessment of medically "proportionate" treatments to the patient's assessment of "ordinary" treatments, consider how this might play out in Mr. P.'s case. Assume that, when Mr. P. was capable, he clearly indicated that he would refuse ANH in this circumstance, on the grounds that it would be "extraordinary" or excessively burdensome to him even if ANH was or would be medically "proportionate" to prolonging his life. Such an advance directive would be morally acceptable if the medical information confirms that Mr. P. is likely to die very soon from complications resulting from his illness and other co-morbid conditions, even if his feeding problem were to be addressed.

If, however, Mr. P. indicated in his advance directive that, when he became severely demented, he intended to end his life in this future state because it would have "no value" or "little value" by insisting that he not receive food or fluids, even if he was willing and able to eat without assistance. Mr. P. would be morally culpable of neglect of self by means of a possibly suicidal directive, and any substitute decision maker or health care provider who followed this directive would be culpable of abandoning him in his demented state.

Case II: Newborn with Down syndrome or Trisomy 21

Consider the case of a newborn with feeding difficulties and a non-lethal but potentially life-shortening condition, such as Down syndrome or Trisomy 21. Assume that medical assessment reveals that the feeding problem in this case is due to poor muscle tone during the newborn period (0-6 weeks) that infants with Down syndrome

sometimes have, and that this problem is likely to improve as the newborn matures.²⁶

This medical information would be relevant to a health care provider's judgment that supplemental feeding by means of a nasogastric tube would not be "futile" unless there is evidence to suggest that the infant is unable to assimilate nutrition and hydration by this means, but a further decision would need to be made regarding whether such feeding is "proportionate" to the overall goal of care for this infant as discussed and agreed upon with the parents in light of medical and moral norms. The medical context of a developing child is often different from that of a functionally declining person in respects that are relevant to this judgment.

Given medical information that the feeding problem of the infant in this case is most likely transient and that the infant, at this time, is otherwise healthy, one would assume that improving the infant's nutrition and likelihood of survival should be a priority of the parents for their child. If the parents were to choose differently, then the reason(s) why they would do so should be explored by the health care provider. If the reason is connected with parental perceptions and attitudes regarding Down syndrome and raising a child with Down syndrome, this could be addressed through education, counselling, pastoral care, and other means. The health care provider could explain that declining feeding would be incompatible with the goal, not only of maintaining nutrition and hydration, and of extending the life of their child, but also of providing him or her comfort. If the basis of the decision of parents still to decline tube feeding is because they judge the life of their child to be of "no value" or "little value", they would be morally culpable.

²⁶ LENNOX N., *Management guidelines: developmental disability*, Melbourne: Therapeutic Guidelines Limited, 2005, p. 226.

This case raises a question regarding the limits of the role of substitute decision makers when forgoing life-prolonging treatments on behalf of an individual who has never had capacity. In the context of making a substitute decision for someone who was previously capable, decision makers should use what has been called an ‘objective standard’ (i.e., medical information about the proportionality of the treatment) and a ‘subjective standard’ (i.e., demonstrable knowledge of this patient’s prior capable negative, and sometimes positive, wishes regarding the use of the treatment in the current or similar circumstances, which would help them to judge the presumed “extraordinariness” or “ordinariness” of the treatment for the patient). For substitute decisions regarding persons who have never been capable, decision makers need to base their decisions primarily on the objective standard, which is why accurate and unbiased medical information in these cases is important.

Considerations regarding the burdens of medically proportionate life-prolonging treatments for the patient, family or others are relevant to determining whether they are “extraordinary” but such considerations are also open to misuse in this setting. The concern is that substitute decision makers will reject medically beneficial life-prolonging treatments because they regard death as the preferred outcome for the patient without due consideration of the patient’s wishes or presumed wishes, and his or her best interests.²⁷ Decisions not to treat persons with physical and/or intellectual disabilities are sometimes based on the view that the lives of such persons have diminished value and that their lives are necessarily “dominated by unbearable suffering” and “incapable of happiness”.²⁸

²⁷ KELLY D., *Medical care at the end of life: a Catholic perspective*, Washington: Georgetown University Press, 2006, p. 42.

²⁸ DE JONG, T.H.R., *Deliberate termination of life of newborns with spina bifida: a critical appraisal*, Childs Nerv Syst 2008 24(1):13-28.

Such a negative assessment of the quality of life of persons with a disability from birth cannot legitimately be made because it is unfair to assume that someone who has never developed certain capacities is likely to experience the same suffering that a non-disabled person might experience with the loss of such capacities.

Case III: Newborn with Trisomy 13

Consider now the very difficult substitute decisions regarding non-treatment faced by those caring for a newborn diagnosed with Trisomy 13 or Patau syndrome. This is usually regarded as a lethal chromosomal abnormality that is associated with a range of medical problems in which the median survival time is 7 to 10 days and 91% of newborns die before one year.²⁹ If a particular newborn with Trisomy 13 has feeding problems similar to the newborn with Down syndrome, the health care provider should not unilaterally judge supplemental feeding by nasogastric tube to be “futile” unless a careful examination of the infant were to reveal that such feeding would or does not deliver nutrition (e.g., if the infant cannot assimilate the food at all due to a congenital malformation that is not correctable). Otherwise, the decision whether to initiate or continue such feeding requires a discussion with the parents about the overall goal of care for their child and a judgment about the proportionality of such feeding to this goal. If a reasonable medical judgment, given the probable nature and incompleteness of the medical information in such situations, is that (1) the infant is unlikely to live beyond one to two weeks because of multiple organ malformations that cannot be repaired, and (2)

²⁹ DUARTE A., MENEZES A., DEVENS E., ROTH J., GARCIA G., MARTINO-ROTH M., *Patau syndrome with a long survival: a case report*, Genetics and Molecular Research 2004 3(2):288-292. See also RASMUSSEN, S.A., WONG, L.C., YANG Q., MAY, K.M., FRIEDMAN J.M., *Population-based analyses of mortality in Trisomy 13 and Trisomy 18*, Pediatrics 2003 111(4):777-784.

the child cannot be kept comfortable and feeding prolongs the evident discomfort of the child, health care providers could authentically judge, in consultation with the parents, that supplemental feeding by nasogastric tube, though “proportionate” to the goal of prolonging life for a very short period of time, would be “disproportionate” to the goal of providing comfort. If, however, nasogastric tube feeding could support keeping the infant comfortable while dying, and would not involve any significant burden for the child and family or cost, then in principle it would both be “proportionate” to providing comfort care and “ordinary”, although, if any of these conditions were to change, withdrawal of feeding could be ethically defensible.

By contrast, if genetic and clinical assessments indicate that a particular infant has trisomy 13 mosaicism (in which only percentage of the cells in this infant carry the chromosomal abnormality), this condition may not affect the infant’s health status as severely as an infant in whom every cell carries this chromosomal abnormality.³⁰ Such medical information is crucial to an adequate ethical analysis regarding nasogastric tube feeding. Even if the infant is still unlikely to live more than a year, in this case the supplemental nasogastric feeding could be judged to be “proportionate” in relation to the goal of palliative care because it could allow time for the infant to develop his or her swallowing function and feed more comfortably. It could also be deemed to be “ordinary” if the burdens of the tube feeding and of living with trisomy 13 mosaicism were not, or did not become, excessive for the newborn. In such a case, the reason(s) why parents would decline, on behalf of their child, such feeding should be probed, and

³⁰ Although individuals with mosaicism, as a group, have a statistically better prognosis, it is difficult to predict the extent of improved prognosis in individual cases. In part, this is because the extent of the mosaicism identified in the tested tissue (e.g., blood) can differ in other tissues (e.g., nervous system).

parents would be morally culpable if they intended their child's death quickly by means of non-treatment because they judged that life to have no value.

CONCLUSION

In this paper I have highlighted three ethically relevant considerations for decisions to withhold, withdraw or refuse life-prolonging treatments: (1) the right intention, (2) the observance of the proper roles of both health care provider and patient (or substitute decision maker), and (3) the authenticity of the fact and value judgments involved. In the care of the incurably ill and the dying, a helpful way of thinking about the distinction between morally acceptable and morally culpable decisions to "allow to die" is to consider not only the intention of the decision maker, which might not always be clear, but also to pay attention to those instances in medical decision making when the health care provider and patient (or substitute decision maker) goes beyond what is appropriate to his or her role and scope of responsibility, and when their judgments are unreasonable given the medical information on hand and at odds with standard clinical judgments.

Calipari's interpretation of the tradition of the ordinary/extraordinary means distinction in Catholic moral reasoning helps to specify concretely how the actual medical decision making process involves a dynamic relationship between health care provider and patients, each of whom contributes a distinctive expertise. Both make fact-judgments as well as value-judgments regarding the same treatment or non-treatment questions. Each should strive to make judgments that are reasonable in relation to the best available medical information and responsible in light of ultimate values, and to

assist the other in making authentic judgments. I have urged that the notion of “medical futility” be defined by certain narrow conditions based on medical information, and have distinguished between judgments regarding futility and those regarding the proportionality and ordinariness of life-prolonging treatments in which the input of the patient or substitute decision maker is necessary. I have also illustrated how the assessments of goals of care and of the proportionality and ordinariness of treatments may change as new medical information comes to light or the situation of the patient changes.

In summary, there are three main questions in decisions regarding non-treatment that need to be addressed: (a) What is the overall goal of care? Answering this question is primarily the responsibility of the patient or substitute decision maker following a discussion with the health care provider in light of medical and moral norms, and both should agree upon this goal; (b) Which treatment options are futile (in the sense that they need not be offered to *anyone* in similar circumstances and with a similar overall goal of care, and could legitimately be refused, if requested), and which require a judgment regarding the proportionality of a treatment to the overall goal of care for this patient? A treatment is “excessive” or “disproportionate” if the likely benefit to this patient is too low or likely to be reversed by a significant risk of serious adverse effects. This involves a value-judgment by the health care provider ranking various alternatives. The health care provider’s role and responsibility is to discuss non-futile alternatives with the patient or substitute decision maker and to recommend his or her ranking of these options; (c) Which of the proportionate treatment options would be morally obligatory (“ordinary”), and which are optional (“extraordinary”) and therefore morally acceptable to forgo in this

particular situation? Answering this question is primarily the role and responsibility of the patient or substitute decision maker, and it involves considering the acceptability of the burdens associated with various proportionate treatment options in light of their benefits in relation to the agreed upon goal of care.

Understanding the distinct but mutually supportive roles and responsibilities of the health care provider and the patient or substitute decision maker helps to specify what medical information is required for each to make authentic fact and value judgments within the sphere of their respective responsibilities. It also clarifies how medical information can sometimes be the basis for distinguishing between morally acceptable decisions not to treat and those that are morally questionable or unacceptable. If the roles and responsibilities of health care providers and patients or their substitute decision makers are executed responsibly and in respectful dialogue with each other, and the death of the patient is not intended by either party, then it would be morally acceptable to limit life-prolonging treatments. It is possible, however, for the parties involved in the decision-making process to fall short of their moral responsibilities, either by overstepping their roles and failing to collaborate adequately in the decision making process, or by failing to make authentic judgments. This results in non-treatment decisions for which they are both morally implicated.

Finally, it is helpful to conclude with a few comments regarding responsible stewardship of one's life in light of the above discussions about foregoing "excessive" treatments at the end of life.

First, it is worth noting that ethical issues concerning incurable illness and dying arise most often in the context of managing the most prevalent chronic diseases, which

account for the most deaths in adults worldwide. These include cardiovascular disease, cancer, chronic obstructive lung disease and diabetes. Two in every three deaths in the world (35 of 58 million deaths) are due to such chronic diseases, and 80% of these deaths occur not in the developed world, as one might expect, but rather in low and middle-income countries.³¹ Many of these chronic diseases are attributable to a small number of known modifiable risk factors, such as hypertension, hypercholesterolemia, diabetes, tobacco and alcohol consumption, sedentary lifestyle, obesity, and in low and middle-income countries, the lack of a healthy diet and access to basic health care.³² Chronic diseases can often be prevented or delayed by reducing these risk factors using relatively simple individual and population health strategies. Effective measures to address these risk factors are neither excessive nor burdensome for individuals or communities. They include, for example, increasing physical activity, reducing weight, decreasing salt and fat consumption, introducing tobacco and alcohol-control measures and using relatively inexpensive medications to normalize high blood pressure and high cholesterol levels. Besides the benefits of preventing many years of ill health, those whose deaths are averted by such measures would live, on average, an additional 18 years. Attention needs to be paid to this issue, which relates to what most of us would judge to be morally ordinary interventions for promoting health and longevity that are not excessively burdensome for individuals or communities and should be available to everyone beginning early in life. Practicing and promoting habits of healthy living and disease prevention strategies should be a hallmark of a culture of life.

³¹ PICARD A., *What are we doing to stop world's no. 1 killer?*, The Globe and Mail, Toronto, December 6, 2007, p. L6.

³² GAZIANO T., GALEA G., REDDY K., *Scaling up interventions for chronic disease prevention: the evidence*, Lancet 2007, 370: 1939-46.

Second, it should be emphasized that thinking about one's care at the end of life, in light of one's spiritual journey, and discussing one's wishes and obligations with trusted loved ones and health care providers should be considered a responsibility that one, when capable and facing a life threatening illness, should undertake. The ultimate question in decisions about forgoing excessive life-prolonging treatments is, what do I hope for before dying? It is both a medical and human question that a life-shortening or lethal illness may force one to confront, and it presses one to articulate what remains to be enjoyed or achieved in order for one to yield up one's life in peace, following the example of Simeon in the bible.

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