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Loi concernant les soins de fin de vie

Advance Directives, the Role of the Family, and Decision Making at the End-of-Life

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Competent patients need an Advance Directive for at least two scenarios:

- Patients at the end of life who want certain procedure to be done to them or not to be done to them. Beyond verbal expression, they also put it in writing and/or video to ensure that the medical care teams know what they want;
- Patients who are about to undergo complicated medical procedures and there is a possibility that their medical condition would be different, for worse, as a result. Patients declare what they wish to do with them.

Advance Directives (Ads) are often made without the opportunities for full informed consent. On what basis did the patient make the decision that she would not want to be treated? The decision not to receive treatment should be based on a clear understanding of the situation. It is essential that the patient really understand the disorder, the available alternatives, and her chances and risks. This can be rather complicated when the physicians themselves do not have a clear picture about the condition and cannot provide a reliable prognosis. Furthermore, preparing and drafting an advance directive is a time-consuming and difficult procedure. Patients and GP's are not always fully informed and instructed on how to prepare an advance directive.^[1]

Moreover, there are valid concerns about the patient's opportunity to change her mind,^[2] the potential for scientific developments, and the clarity of the advance directive. In a patient who is mentally alert and who makes a decision not to receive treatment, there is always the opportunity for the clinician to consider with the patient the reason for the decision in light of the particular clinical features. The clinician also has the opportunity to discuss with the patient why she does not want treatment. Is it fear of pain, loss of dignity, concern for others, etc.? In these circumstances, the clinician is in a better position to ensure that the patient has thought out the decision carefully. This possibility is removed when faced with an AD and an incompetent patient.^[3]

As for the potential for scientific progress, competent patients have the advantage of making their decision based on up-to-date knowledge. Advance directives may be

¹ Guda Scholten, Sofie Bourguignon, Anthony Delanote et al, Advance directive: does the GP know and address what the patient wants? Advance directive in primary care, *BMC Medical Ethics* 19 (2018):58.

² Daniela J. Lamas, When Faced With Death, People Often Change Their Minds, *NY Times* (Jan. 3, 2022).

³ Keith Andrews, "Euthanasia in Chronic Severe Disablement," *British Medical Bulletin*, 52(2) (1996): 287.

made many years prior to the time of their implementation, a period during which new treatment or changes in quality of life opportunities may have occurred. In addition, ADs are not always clear about the patient's intentions. A leading British physician, Keith Andrews, testifies that he saw an AD stating that if the person developed severe brain damage she would not want to continue living. There was no statement as to whether this decision was to be made on the first day or after a period of several days/weeks/months to give the patient opportunity of recovery. The general statement about severe brain damage gives wide latitude for widely differing views, even among clinicians experienced in the management of brain damage.^[4]

In the Netherlands I saw ADs saying: I'd like to die upon the stage when I don't recognize my children.^[5] This phrasing is far too vague and too sweeping to serve as guidelines. It provides health care professionals with wide latitude for interpretation that might not always be in tandem with the patient's best interests. Medical conditions are varied and complex. ADs that are usually phrased in general terms might be ill-suited to serve as guidelines to follow. The decision-making process should consider further factors, most importantly the particular medical condition of the patient and the feasibility of maintaining a reasonable quality of life that is of significance to the patient in concern. The AD together with family testimonials can shed light as to whether the present quality of life is reasonable for the patient and of significance to him or her.

We should be wary of the impact that financial considerations may have in deciding the fate of the patient. In the US, there are fears that ADs will be utilized against the patient's best interests to save costly resources. It has been argued that advance directives have not fulfilled their promise of facilitating decisions about end-of-life care for incompetent patients. Furthermore, many legal requirements and restrictions concerning advance directives are counterproductive.^[6] The advance directive must be applicable to the present circumstances. The medical care team should consider the length of time that has passed since making the advance directive, changes in the patient's condition, the circumstances that the patient is now in, and the likelihood of successful treatment.

In Israel, the 2000-2002 Steinberg Committee recognized ADs but insist that they will be refreshed every certain no. of years. This is because the procedure of advance directives reflects competent values and interests in circumstances where they might no longer be applicable. If the patient is incompetent at the time the procedure becomes effective, withdrawal or withholding of medical treatment constitutes a form of imputed consent. The situation of the incompetent patient is

⁴ *Ibid.*, p. 287.

⁵ Raphael Cohen-Almagor, *Euthanasia in the Netherlands: The Policy and Practice of Mercy Killing* (Dordrecht: Springer-Kluwer, 2004). See also Cohen-Almagor, *The Right to Die with Dignity: An Argument in Ethics, Medicine, and Law* (Piscataway, NJ.: Rutgers University Press, 2001), Chapter 7.

⁶ Bernard Lo and Robert Steinbrook, Resuscitating Advance Directives, *Arch Intern Med.*, 164 (2004), 1501-1506. See also A. Fagerlin and C.E. Schneider, Enough. The failure of the living will, *Hastings Cent Rep.*, 34(2) (2004):30-42; End of life directives have little impact, *UPI Science News* (7 April 1997). For contrasting view, see B.H. Levi and M.J. Green, Too soon to give up: re-examining the value of advance Directives, *Am J Bioeth.*, 10(4) (2010): 3-22.

viewed through the lens of her prior competent self rather than her current state. It is usually assumed that the justification for giving the competent person power over decisions when she is incompetent is that the competent person is best situated to identify what those future interests will be. The problem, however, is that the patient's interests when incompetent are no longer informed by the interests and values she had when competent. The values and interests of the competent person are no longer relevant to someone who has lost the rational structure on which those values and interests rested. Although still the same person, the patient's interests change radically when she becomes incompetent. Thus, there is a possible conflict between past competent and current incompetent interests.^[7]

To resolve the conflict between past competent and current incompetent interests, it is suggested that instead of simply enforcing all prior directives, doctors, families, and other people involved in the care of incompetent patients should be able to examine whether the patient's interests would best be served by actions contrary to the AD, in situations in which the incompetent patient appears to have an interest in further treatment and life.^[8]

Pertinent considerations

Summing up the considerations that are important in decisions on death with dignity, I would say the following: if the patient makes advance directives in the form of a living will, DNR order, a letter, etc., that she would wish to continue living, no matter what, and we have no reason to believe that the patient changed her mind, then we should respect that wish.

In the event the patient prepared an AD saying that she would prefer that all treatment be terminated upon reaching the last stage of their incurable disease, and we are uncertain about the patient's present wishes because, for instance, she is incompetent and the attending physicians think that the situation is irreversible, then we should respect the AD and let the patient die. For persons who prepared ADs asking to die upon reaching a certain situation, death is not the worst situation one can be in when compared to being on the verge of death and then stabilized without hope of ever really getting better. Patients who suffer from incurable diseases (like cancer) may feel that their lives become transient and that the thought of death brings them more comfort than alarm. They may feel that their dignity, their autonomy, their humanity are better served by letting them die. The patient's wish

⁷ John A. Robertson, "Second Thoughts on Living Wills," *Hastings Center Report*, 21(6) (November-December 1991): 6–9, at 7.

⁸ John A. Robertson, Second Thoughts on Living Wills. *Hastings Center Report*, *Hastings Center Report*, 21(6) (November-December 1991): 6–9, at 8. For further discussion, see Advance Decisions and proxy Decision-Making in Medical Treatment and Research, *BMA* (June 2007); Stephen Bonner, Are advance directives legally binding or simply the starting point for discussion on patients' best interests?, *BMJ*, 339 (2009): b4667; Marika Davies, Are advance directives legally binding or simply the starting point for discussion on patients' best interests? *Legal Advice*, *BMJ*, 339 (2009): b4693; Kevin Mackway-Jones, Are advance directives legally binding or simply the starting point for discussion on patients' best interests? *Medical opinion*, *BMJ*, 339 (2009): b4697; B.H. Levi, Green MJ. Too soon to give up: re-examining the value of advance directives, *Am J Bioeth.* 10(4) (2010): 3-22; R. Cohen-Almagor, The Role of the Patient's Family, Surrogate and Guardian at the End of Life, *European Journal for Person Centered Healthcare*, 7, Issue 3 (2019): 454-465.

must be respected. This is especially true if the patient has emphasized beforehand that her dignity cannot be separated from consideration of her loved people. For some patients, knowledge of the anguish their condition imposes on their families is such a heavy burden that they prefer to die and not be remembered in their diminished condition. This, of course, is not the sole consideration but a significant additional consideration that needs to be taken into account.

If no ADs are available, we should ask the advice of the patient's beloved people who should know the patient better than anyone else. If the patient's loved ones believe the patient would want to be kept alive, then we should respect their decision, even if the attending physicians disagree. In the event that the patient's beloved people wish to withhold treatment and the attending physicians think there is still a hope of recovery, then we have to respect the physicians' decision. The patient's best interests require erring on the side of life.

In the event that the patient's beloved people and the attending physicians believe the patient's condition will only deteriorate, and that that condition negates her dignity, the best interests of the patient require allowing the patient to die. I repeat: the best interests of the *patient*, not those of the family or other beloved people, the physician, or the hospital or the society at large.

A word on patient's autonomy

Accordingly, the view is that individuals should be left to govern their business without being overwhelmingly subject to external forces. We are said to be free when our acts are not dominated by external impediments, thus enabling us to form judgment, to decide between alternatives, and to act in accordance with the action-commitments implied by our beliefs.^[9]

Choosing the best option or thinking correctly is not a requirement for autonomy so long as the doer exercises deliberation in assessing the alternatives. The emphasis is not on deciding the "best" options, or on holding the "true" opinions, but on the way in which we come to make the decisions and to hold our opinions.

Some words of explanation are in order regarding the term "deliberation." Deliberation assumes some degree of rationality on the part of the doer. It presupposes a process of examining alternatives in an effort to determine which course of conduct to pursue. When agents think new factors have emerged that deserve consideration, which - on balance - seem important enough, they may decide to re-evaluate the previous decision and reshape their behavior. We choose autonomously when we identify and evaluate the relevant factors pertaining to the choice.

⁹ V. Haksar, Autonomy, Justice and Contractarianism, *British Journal of Political Science* 1973; 3: 487-509; J. Rawls, Kantian Constructivism in Moral Theory, *The Journal of Philosophy* 77(9) (1980): 515-572; G. Dworkin, *The Theory and Practice of Autonomy*. Cambridge: Cambridge University Press, 1988; R. Cohen-Almagor, *The Boundaries of Liberty and Tolerance*. Gainesville, FL: The University Press of Florida, 1994; Autonomy in Moral and Political Philosophy, *Stanford Encyclopedia of Philosophy* (2015), <http://plato.stanford.edu/entries/autonomy-moral/> ; Eric Vogelstein, Autonomy and the Moral Authority of Advance Directives *Journal of Medicine and Philosophy* (2016).

Building on the experience of Belgium and other countries,^[10] I suggest the following: Research has shown that the major reasons which drive patients to ask for death are despair, mental anguish, feelings of hopelessness, loss of autonomy, the fear of losing one's dignity, and physical discomforts such as pain, nausea and exhaustion.^[11-12] In a survey conducted in Washington State, losing autonomy, lack of ability to engage in enjoyable activities, loss of dignity, and inadequate pain control or concern about it were mentioned as the most common reasons that brought patients in to ask for assistance in dying during 2010.^[13] Similarly, the Oregon 2011 survey shows that the most commonly expressed concerns of those dying from physician-assisted suicide were, as in previous reports, lack of ability to engage in activities making life enjoyable, losing autonomy, and loss of dignity. One third of patients had inadequate pain control or concern about it.^[14]

At times, the patient's decision might be influenced by severe pain. This is especially true for cancer patients. The majority of the patients who request euthanasia in both Belgium and the Netherlands are cancer patients.^[15] There are many components to cancer pain and all relevant physical and psycho-social factors need to be taken into account.^[16] A broader knowledge of the ethical background of hospice care and its practical implications needs to be further developed in Belgium.^[17] If it is possible to prevent or to ease the patient's pain, then the patient's request for assisted suicide should not be fulfilled; instead, the necessary treatment should be prescribed. This is provided that the educated patient (i.e., a patient who was advised by the medical staff about the available palliative care options) does not refuse to take the painkillers, and that when the pain subsides so does the motive (or one of the main motives) for assisted suicide. If the patient insists on denying all medication, then doctors must first try to find the reasons for this insistence before they comply with the request.^[18 19 20] There is a need to involve palliative care

¹⁰ SAMS, *Advance Directives*. Switzerland 2017; R. V. Viola, N. Di Fazio, Z. Del Fante et al, Rules on informed consent and advance directives at the end of-life: the new Italian law, *Clin Ter* 171(2) (2020): e94-96.

¹¹ R. Cohen-Almagor, *Euthanasia in the Netherlands: The Policy and Practice of Mercy Killing* (Dordrecht: Springer-Kluwer, 2004).

¹² Oregon's Death with Dignity Act - 2011, <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year14.pdf>

¹³ Executive Summary, *Washington State Department of Health 2010 Death with Dignity Act Report*. Washington State Department of Health, 2011.

¹⁴ Oregon's Death with Dignity Act--2011, Oregon Public Health Division, <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year14.pdf>

¹⁵ R. Cohen-Almagor, *Euthanasia in the Netherlands and Euthanasia policy and practice in Belgium: critical observations and suggestions for improvement*, *Issues Law Med* 24(3)(2009): 208-10.

¹⁶ NHS, *Adult pain management guidelines*, Hull and East Riding Clinical Policy Forum, September 2006.

¹⁷ S. Salloch, Breitsameter C, Morality and moral conflicts in hospice care: results of a Qualitative interview study, *J Med Ethics* 36 (2010): 588-92.

¹⁸ J.V. Lavery, Boyle J., Dickens BM., et al, Origins of the desire for euthanasia and assisted suicide in people with HIV-1 or AIDS: a qualitative study, *Lancet* 358 (2001): 362-7.

consultants so as to enhance the general knowledge and experience of physicians in palliative care.^[21 22 23] but it does not require consultation with a specialist palliative care team prior to the act of euthanasia as the Flemish Palliative Care Federation recommended.^[24] A recent study shows that only 55.4% of GPs had followed a training programme in palliative care or were members of a palliative care team.^[25] It is suggested that GPs who provide euthanasia to their patients should all undergo such training.

A word about myself: I have been studying end-of-life concerns since 1991. I was a member of the Israel Public Committee on the Dying Patient that drafted the *Dying Patient Law* (2005), the only member (of sixty) who supported the legislation of physician-assisted suicide (PAS). Recently I was invited to consult British organizations that promote PAS. In both countries, antagonists emphasise the Belgian (and the Dutch) models as erroneous, as both countries seem to push rapidly the right to die at the expense of the right to life.

Lessons from Belgium

The *Euthanasia Act* was passed in Belgium only in 2002, and the country is still in the learning stages. Looking at the short history of the euthanasia law, policy and practice, may lead us to worry that there is something intoxicating about the practice, leading decision-makers to press forward further end-of-life practices without paying ample attention to caution. One safeguard after the other is removed to allow greater scope for euthanasia. Tolerance towards the practice is enlarged so as yesterday's red lines become obsolete today, and as one red line is removed practitioners and law-makers are already debating a further step and other groups -- patients who are tired of life, now young patients, next demented patients -- to be included within the more liberal euthanasia policy. This is quite astonishing as human lives are at stake. What is required is a careful study, accumulation of knowledge and data, addressing the above concerns, learning from mistakes and attempting to correct them before

¹⁹ J.J. Georges., The AM., Onwuteaka-Philipsen BD., *et al*, Dealing with requests for euthanasia: a qualitative study Investigating the experience of general practitioners, *J Med Ethics* 34 (2008): 150-5.

²⁰ A.L. Back, Pearlman RA., Commentary: desire for physician-assisted suicide: request for a better death?, 358, No. 9279, *Lancet* (2001); 344-5.

²¹ J.L. Bernheim, Deschepper R., Distelmans W., *et al*, Development of palliative care and legalisation of euthanasia: antagonism or synergy?, *BMJ* 336 (2008): 864-7.

²² A. Kuin, Courtens AM., Deliens L., *et al.*, Palliative care consultation in the Netherlands: a nationwide evaluation study, *J. of Pain & Symptom Management* 27(1) (2004): 53-60.

²³ R. Cohen-Almagor, Dutch perspectives on palliative care in the Netherlands, *Issues Law Med* 18(1) (2002): 111-126. See also J. Zenz, Tryba M, Zenz M. Palliative care professionals' willingness to perform euthanasia or physician assisted suicide. *BMC Palliat Care* 14 (2015): 60.

²⁴ B. Broeckaert, Janssens R., Palliative care and euthanasia. Belgian and Dutch perspectives, in P. Schotsman and T. Meulenbergs (eds.), *Euthanasia and Palliative Care in the Low Countries*. Leuven: Peeters (2005): 35-69.

²⁵ Y. Van Wesemael, Cohen J., Bilsen J., *et al.*, Implementation of a service for physicians' consultation and information in euthanasia requests in Belgium, *Health Policy* (online 5 January 2012).

rushing like frenzy to introduce more liberal ways to euthanize patients. I call upon the Senate: Wait. Study. Reflect. Move forward with the obligatory caution. A fine line distinguishes between ethics and policy. It is your role to draw this line prudently. Haste makes waste.

Since the enactment of the Euthanasia Law, the practice of euthanasia has been expanding. The number of euthanasia cases is increasing. Euthanasia is no longer limited to terminally ill patients. It may be applied to patients with chronic degenerative diseases. People who are depressed, who are unhappy with their lives, were euthanized. Ending patients' lives without request or consent is a lingering problem. Terminal sedation is widely practiced, a procedure that does *not* require the patient's consent. At the same time, research highlights the physicians' confusion and lack of understanding of the *Euthanasia Act*, the problem of inadequate consultation with an independent expert, and the problem of lack of notification of euthanasia cases. Shouldn't Belgium and other countries that proceed in the same path, like Canada, address these nagging and troubling concerns before rushing to enlarge the scope of euthanasia to include children? Can a proxy adequately represent the best interests of the child? Provide guidance and required maturity to understand the complexity of issues.

The first medical duty is Do No Harm. It is also *your* duty.