The Right to Die with Dignity. A Discussion of Cohen-Almagor's Book

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ABSTRACT

Cohen-Almagor's book represents a remarkable contribution to the discussion of the right to die with dignity. It offers the discussion of a wide range of topics. They include: the terminology respectful of human dignity (where, for example, 'post-coma unawareness' is suggested instead of 'permanent vegetative state'); the question of autonomy; the sanctity-of-life – quality-of-life debate; criticism of some extreme quality-of-life position; criticism of Ronald Dworkin's distinction between critical and experiential interests and the consequences this author draws from it; active and passive euthanasia; the Dutch experience and the Oregon Death with Dignity Act; and many others. The book is discussed from a basically sympathetic view, where some details are focused on as meriting some further examination. Some remarks are offered to indicate the complexity of the definition of autonomy; a defense of Dworkin's argument is offered; an insistence on the necessity to rely on moral conferring features is remarked.

1. Raphael Cohen-Almagor offers us a really comprehensive, rich of background information and critically considered discussion about questions of death and the choice of death in the context of the medical practice (1). His book includes several chapters on the topic, and I will discuss some of them. I am very much sympathetic with most of Cohen-Almagor's argumentation. However, I leave to a direct reading the possibility to appreciate in details most of the numerous virtues of the book. Here I address those parts of the book that, in my opinion, deserve some further discussion. I think that this is the best way to express the richness and the wide range of virtues exemplified in this book.

In the Introduction, Cohen-Almagor ponders the most general terms of the debate between those that hold the sanctity of life principle and those that hold the principle of autonomy as inspiring and shaping the discussion on the right to die. Supporters of sanctity of life find human life as inviolable, and do not accept reasons to terminate it. Supporters of the autonomy-based approach allow the interested subjects to decide about whether life has still any meaning for them. This implies (with some qualifications, as we will see later) the right to choose death.

Now, I think we can fairly be satisfied with the definition of the sanctity of life doctrine,
which is, by itself, put in very clear terms. There is still a problem with the rival doctrine. What is exactly 'autonomy', that is to be respected? Cohen-Almagor says the following: «Choosing the best option or thinking correctly is not a requirement for autonomy so long as we assess the alternatives carefully. The emphasis is not on deciding on the best options or on holding true opinions, but rather on the way in which we come to hold our convictions and make our decisions. The crucial thing for autonomy is the possibility that an individual has to reflect about her own beliefs and ideas, as well as the ability to form ideas about them, in order to decide how to live. In order to make choices we need a range of options to choose.

This is the conception of autonomy frequently adopted by liberals, like Cohen-Almagor. Although this is not very usual in books on bioethics, it seems to me that the concept of autonomy deserves a little more theoretical and analytical specification. It may be useful, for example, to distinguish this concept from that of Immanuel Kant, in order to specify the superiority of the present concept. According to Kant, autonomy is the property of an agent who makes decisions according to pure practical reason, and acts according to the unconditioned duty. If the subject acts by following her natural inclinations, she is not autonomous. A consequence of this, according to Kant, is that if the subject chooses death in order to avoid pain, she follows a natural inclination and is not autonomous. This is obviously not the case if one follows the concept of autonomy endorsed by Cohen-Almagor. In his case, it is enough that the individual considers the different options and chooses for one of them. If the subject reflectively evaluates that her life, perhaps due to strong pain, is not any more valuable, or does not find any more meaning in it, then she is allowed to choose death. But this may be exactly the choice to surrender to a natural inclination, i.e. of heteronomy and not of autonomy, as a Kantian would say. As it is known, there are influential Kantian arguments against suicide that rely on this complex interpretation of autonomy, and these arguments, although reformulated, are used in contemporary debates, as well.

Another point may be this one. An individual can be in the position of not having ever thought about diverse opportunities in her life. She was raised in a conservative community, and she acknowledged only one moral outlook in her life. It seems to me that there may be a sense in which we can say that there is some practical necessity in what she does. There are no really available opportunities to her, because she has never had a real opportunity to reflect about different options. Is her choice autonomous? If not, does she deserve the right to choose in matters of death? Intuitively, it does not seem to me that she deserves this right less than an individual raised in a multicultural community, distinguished by multicultural education. But, the second individual satisfies Cohen-Almagor's definition of autonomy, while the first does not. At least, this seems to me.

These are obviously questions at a rather abstract theoretical level, and I do not find as crucially relevant, in a book on the right to dignity which has strong applicative interests, the absence of the more detailed discussion of the questions that I have raised. In his background discussion, the author reflects on prominent philosophers in the liberal tradition, like John Rawls and Joseph Raz.
2. Cohen-Almagor shows concern for the correct way of language usage, in a way that it is not damaging the patients' interests. He opposes the usage of the expressions 'terminal' and 'persistent vegetative state'. Instead of 'persistent vegetative state', Cohen-Almagor proposes 'prolonged unawareness' and 'post-coma unawareness'. The term 'coma' is limited to cases where three elements are present: closed eyes, no utterances of meaningful sounds, and no adequate motor reaction to external stimuli. The terms suggested by Cohen-Almagor are intended to be mere technical terms that need to substitute the term 'vegetative' which dehumanizes patients, and is offensive to their dignity, as well as to the dignity of their loved ones. Cohen-Almagor finds a connection between the use of the term 'vegetative state' to the term vegetable, which is ethically impermissible. An equivalent way of thinking is developed by Cohen-Almagor in relation to the expression 'terminal'. This term suggests a picture in which the medical staff is only waiting for the death of the patient, while, on the other hand, human life deserves full respect and care until the last moment.

This part of Cohen-Almagor's book is interesting from various standpoints. One of them that is surely remarkable is the indication that authors that accept the right to choose in matters of death are not, by this same fact, expressing a loss of respect, or consideration for human life. Cohen-Almagor considers with great balance the respective weight of the value of autonomy, as well as that of human life in general. This is one of the greatest merits of the book.

When discussing post-coma unawareness patients (a condition that comprises reversible damages of the brain cerebrum, that is the possibility of a way back to a meaningful life and which must be distinguished from brain death), Cohen-Almagor indicates that it is not acceptable to take as a normal clinical practice to deny forms of care to them. In the case of brain death (which includes the death of the brain stem), there are irreversible damages that do not permit to return to a meaningful life. Cohen-Almagor urges hospitals as a policy not to cease treatment of post-traumatic post-coma unawareness patients younger than 50 years old within a period of less than two years. The two-year waiting period should be regarded as the minimum period of evaluation before forgoing hopes for patients' rehabilitation and return to some form of cognition. The study provides data and human stories from the Israeli experience as well as from England, Canada, the United States and other countries to substantiate this argument.

3. In the third chapter Cohen-Almagor considers the debate between the sanctity of life doctrine and the quality of life doctrine. The former attributes value and absolute protection to human life as such. The latter considers the content of life, as the value-attaching feature. I will show in some details Cohen-Almagor's criticism of some exemplifications of the quality of life doctrine, in particular, those of Helga Kuhse and Peter Singer. In their opinion, life can be evaluated, so that, for example, the life of a mature, autonomous, and healthy person is more valuable than that of an anencephalic infant. Kuhse and Singer refute the criterion of evaluation of life that refers to species belonging. What matter are value-conferring features, like those indicated above. Cohen-Almagor opposes this view. According to him, «What makes people worthy of respect is their humanness, the fact that people are people, whether or not they have a
capacity for self-determination, adoption of ideals, or a sense of the future. When human life begins, it is important that it will continue with dignity and with respect. We give people respect because we value life as such, in itself» (5). This is not to take a stance for the denial of physician-assisted suicide. It may happen that life becomes for us so painful that we choose death as a better option.

Cohen-Almagor finds Kuhse's and Singer's position incoherent. On the one hand, they do not attribute full protection to the life of infants (in virtue of the absence of actual value-conferring features); on the other hand, they require that society engages in allocation of resources for disabled people. In fact, they qualify their statement related to the protection of children. They say that they are denying full protection only to the life of disabled infants. This, according to them, permits to allocate resources so that adult disabled people are helped in a better way.

Cohen-Almagor thinks that the adoption of Kuhse's and Singer's proposal originates dangerous social consequences. One of them is the irresponsibility of the parents who may too easily adopt infanticide. Or, mothers can be irresponsible in their pregnancy, not renouncing to elements in their life that may be dangerous for the future person, in virtue of the fact that they may make use of infanticide if something goes wrong.

Cohen-Almagor declares himself as a speciesist, and he cares first of all about our own species, us human beings. He thinks that newborn infants have a right to life, merely in virtue of the fact that they are human. According to him, there is nothing worrying in this, and he says «it is only a human and preferable inclination to think first about our fellow humans. It is also natural for an elephant to think first and foremost about its fellow elephants» (6). Cohen-Almagor opposes some very radical Singer's stances, for example, that the killing of a chimpanzee is a more serious act than the killing of a human being with intellectual defects. Moreover, Cohen-Almagor thinks that there is a mistake in Singer's proposal when he attributes no moral weight to the killing of a human life deprived of intellectual capacity. The mistake is due to the fact that this life can, nevertheless, be evaluated as deserving dignity by other people in virtue of, for example, love of family members, or religious reasons.

This is the part of Cohen-Almagor's book that I find most questionable. Let's start from the last part. It is true that there is something disturbing in the terminology in the description Singer gives to his theory. However, it seems to me that some aspects of Cohen-Almagor's criticism of Singer's stance are overstated. First, it seems to me that Singer does not exclude the possibility that some lives may have to be respected even when losing the value-conferring feature. Singer explicitly says that a life may deserve protection in virtue of the fact that some people may attribute value to it. When, in his Practical Ethics, he says that newborn infants do not possess value-conferring features, he adds that there is a difference between newborn infants with serious defects, and healthy newborn infants. In the second case, we have an event that is a happy event for people in full possession of rights (7). We can see, surely, an important omission, in Singer's explanation of his theory. This is the exclusive statement that only the life of a healthy infant can represent a joyful event for the parents. However, there is something relevant, and its presence in Singer's thought deserves to be remarked, contrary to what Cohen-Almagor does. It is the fact that value can be attributed indirectly to some beings.
The indirect way is the value attributed by people in full possession of a moral status. But if this is permitted, then the consideration of some people for some beings may represent a reason to attribute value to all newborn infants, and to all human beings, independently of the fact whether they are defective or not. It seems to me that Singer's rhetoric is directed toward those people who do not want to permit cases of euthanasia absolutely, like the defenders of the sanctity of life doctrine. But, it would be quite incoherent with what he says to interpret that euthanasia becomes something that can be imposed on parents that do not want it, or that it is legitimate to declare a life as fully losing value despite the attitude of the parents, as it may appear from Cohen-Almagor's criticism of Singer.

Second, it seems to me that there is not such a plain contradiction in engaging for the euthanasia of defective newborn infants (when it corresponds to the wish of the parents), and the statement that this is (also) in order to help in a better way defective adults. This discussion reminds that regarding prenatal screening, opposed by people who fear that this practice may create a presumption contrary to disabled people. Philip Kitcher convincingly shows that this is mistaken attitude (8). He indicates examples of situations where programs directed toward the reduction of the incidence of genetic disabilities come together with an increasing of the support for disabled people already born. If this is true, I do not see any serious reason to deny that the permission of euthanasia (provided the consent of the parents) in the case of newborn defective infants can come together with the sustain of a program of support for adult disabled people.

In relation to a kind of slippery-slope argument that Cohen-Almagor offers, according to which parents may come too easily to adopt infanticide, or, mothers may behave irresponsibly during their pregnancy, in virtue of the fact that they may make use of infanticide if something goes wrong, I must say that I do not find the arguments really convincing. It appears to me that most of the people have a strong emotional attitude toward their children, and that infanticide can be only a last resort in desperate cases, as far as we know about radical features in human behavior. In any case, if the attitude changes becoming a worrying social occurrence, it is possible to change the rules when this becomes a clear and present danger. As for the possibility of increasing the irresponsibility of the pregnant woman, I do not see any reason why the permission of infanticide would have any effect on this attitude, more than this is done by abortion. I do not find Cohen-Almagor's declaration for speciesism convincing as well. I think that there are reasons to privilege our fellow members of our species, but the reason cannot be the simple appeal to the naturalness of this. I guess that it is a wide shared attitude to evaluate with particular strength humanity as related to the possibility of critical moral thinking. But if this is true, we cannot embrace a behavior simply because it is followed by other animals, that act only instinctively. This would be to renounce to a relevant aspect of humanity. A moral attitude is adopted in a way respectful of humanity only reflectively. But it appears too limited a reflection that appeals to a similarity of an attitude with that shared by animals not capable of critical thinking.

However, I must say that I do not embrace Singer's and Kuhse's version of the quality of life doctrine, and I think that valid arguments can be offered against it. This is the reason why, although I am not very much convinced by Cohen-Almagor's criticism of
these authors, I am, nevertheless, very much in sympathy with his proposal for only limited legitimation of quality-of-life considerations in the evaluation about whether it is morally appropriate to end a life.

Cohen-Almagor does not refute all possible kinds of consideration of quality of life. Although there is a sense in the preservation of life, this is not absolute. «The Kantian view that conceives of people as ends rather than means leads to the conclusion that life is not sanctified when the continuation of life harms human dignity and contradicts the patient's best interest» (9). The concept of quality of life is subjective, and the crucial question is about the will of the patient. However, there are three fundamental elements in determining quality of life, i.e. consciousness, lack of suffering, and dignity. The relative importance of each of them depends on single patients. Considerations of quality of life have implications in various directions: the financial aspects, the doctor-patients relationship, relationships with the surroundings, the effects on the patients themselves.

4. As usual in the discussions about the right to dignity, Cohen-Almagor discusses active and passive euthanasia. Some authors find this distinction relevant, in particular in virtue of the moral significance of the difference between killing and letting die. Cohen-Almagor thinks that the will of the patients to die with dignity (in the way they find dignified) deserves serious consideration. «Medicine and ethics should address their needs. Although this is not an easy task, the solution must not be beyond our reach, either medically or ethically. That solution might change the nature of medicine, but the nature of medicine is not a static concept» (10). However, Cohen-Almagor does not advocate active euthanasia but rather physician-assisted suicide, in virtue of possible abuses.

There is one specific case when Cohen-Almagor opposes active euthanasia with a particular motivation, and this is in the discussion with Ronald Dworkin (11). Dworkin distinguishes between experiential interests and critical interests. The former are related to a subject who is aware of what happens to her, and wants to find pleasure in the fulfillment of her desires. The latter are related to the accomplishment of a worthwhile life. Dworkin thinks that critical interests render human life valuable, and, therefore, it is their satisfaction and protection that matters. Related to the question of the present discussion, Dworkin says that many people do not want to be remembered for the part of their life that they found degrading. The most interesting and controversial part of the discussion regards cases of Alzheimer's disease. Dworkin compares the part of the life of the subject that has expressed some wishes when she was able to do this, in particular wishes not to live in a situation like that included in the Alzheimer's disease, and the life in that condition. In the former case, we have critical interests of the subject (the accomplishment of a life plan), in the latter only experiential interests (like avoiding pain, or that of getting a piece of bread with butter). In Dworkin's opinion, there is nothing valuable by itself in the latter case, and this is the reason why the wish expressed by the subject in the former condition has to be respected.

Cohen-Almagor criticizes this proposal. He thinks that life can be valuable even in the case of an advanced condition of Alzheimer's disease. Moreover, he says that the present desires of the subject have to prevail on those formulated earlier. The crucial
argument is that it is not true that our directives are predetermined and unchangeable, and we are not able to know how our lives will look in front of death. Cohen-Almagor thinks that the notion of unchangeable and unified personality is questionable. «Indeed, the very idea of autonomy reflects our ability and desire to construct and reshape realities, to reevaluate values and ideas, to renounce to old beliefs, and to accommodate ourselves to new situations» (12). In particular, Cohen-Almagor questions Dworkin's statement that human beings, as rational agents, can establish in advance what will be their preference. On the contrary, Cohen-Almagor thinks that human beings are not only thinking creatures. People sometimes act, or are pushed to act, on the ground of their sentiments, instincts, impulses, and, in general, by factors that it is difficult to explain rationally. All this opens the question whether advanced directives are invalid when the patient is incompetent. «It is usually assumed that the justification for giving the competent person power over decisions to be made in the future, when he or 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 incompetent patient's interests are no longer informed by the interests and values he or she had when competent» (13).

Cohen-Almagor's solution is now quite different from Dworkin's. Dworkin says that it is respectful of the human being to show full consideration for her advanced directives, because they are related to her exercise of autonomy. Cohen-Almagor thinks that no such mechanical attitude may be taken. «Doctors, family, and others involved in the care of incompetent patients should be able to examine whether patient interests would best be served by actions contrary to the living will, in situations in which the incompetent patient appears to have an interest in further life» (14). In brief, by using Dworkin's terminology, Cohen-Almagor says that the experiential interests in the present are more important than critical interests voiced in the past. «What may seem experiential in one stage of life might in a marred, limited life become critical to our being. For some demented patients the taste of vanilla ice cream and the smell of lilies might be essential to the definition and conception of life» (15).

I find questionable this part of Cohen-Almagor's discussion, and the reasons for my worry are the same as those I indicated when debating the question of speciesism. Cohen-Almagor attributes high moral consideration to human life as such. This is the reason why he finds that all moments of human life deserve equal consideration. On the other hand, the same as, I think, is Dworkin's opinion, it seems to me that some criteria and distinctions have to be established. In my opinion there are specific value-conferring and right-conferring features of human beings that are crucial in establishing our moral status. These are, primarily, the capacity to be rational and reasonable (in Rawls's terminology) (16). This does not mean that human life has not value in some conditions, but it does mean that some considerations of moral priority may be put forward, and these considerations are different from Cohen-Almagor's, while they are apt to support Dworkin's view.

If it is rational and reasonable capacities that are the primary value-conferring features to human beings, the will of the human being, while she was able to formulate her life plan, has priority over other considerations. The life condition that comes after the person has lost cognitive capacities deserves moral respect, but primarily in virtue of the
human being that was owner of a high moral status. In the case of conflict, the most pressing considerations are overriding. In the specific case, this is the respect of the will of the person when she was able, as a reasonable and rational person, to formulate a life plan, and she did this. More precisely, in the case of the Alzheimer, the will of the person in the full possession of her mental capacities must be respected. It is true, as Cohen-Almagor says, that a life plan is not unchangeable. However, a life plan is changeable if the person is still able to formulate, or rethink about it. When a subject loses the capacity to be rational and reasonable, she does not have any more a life plan, and cannot reformulate it. Her life plan comes to the end, and the relevant problem is, as Dworkin says, the way this end will look like. The dilemma is whether the end will look like the person wanted, or in another way. It is true, as well, that there are life conditions when a person finds as valuable things that she even did not consider as relevant earlier. I can speak about my personal experience in a case that is banal as compared to the dramatic situations discussed here. When I was in the army and, for weeks, had the possibility to eat only the (rather disgusting) food we had, I found a pleasure, and a value, in vanilla ice in a way that I never imagined earlier. Here I agree with Cohen-Almagor. There are life situations when we reshape our life plan, because the conditions are new, and previously even not imaginable. However, I am ready to agree with this if we are speaking of someone who is still a rational and reasonable person. In the other case, I would disagree with the attitude of attributing a life plan to a subject. In particular, I do not find convincing Cohen-Almagor's statement that «What may seem experiential in one stage of life might in a marred, limited life become critical to our being. For some demented patients the taste of vanilla ice cream and the smell of lilies might be essential to the definition and conception of life». Unfortunately, in the stage of life we are discussing, nothing has the possibility to become critical, and there is, unfortunately, no more definition and conception of life. There is exactly what is indicated by Dworkin, the presence of experiential interests. Otherwise, it would be required to attribute a definition and conception of life to other animals with similar cognitive capacities, which is, I think, unconvincing. This is not enough to say that human life, in any stage, may become morally comparable to the life of other animals. As I said, I think there are reasons to attribute a special concern for human life, anyway. However, there is a privilege for the will expressed in some moments of life, in comparison to desires existing in another moment of life. This is the case of moral dilemma, and, like in every situation of moral dilemma, the choice is tragic.

5. One of the great merits of Cohen-Almagor's book is the verification of euthanasia in practical life. In order to possess direct evidence, Cohen-Almagor investigated the Dutch situation. He found there a set of troublesome results. Although there is a wide agreement on the acceptability of euthanasia, people do not seem to endorse the practice with the required reflectivity. Cohen-Almagor found that it is not always the patient who makes the requirement for euthanasia. Sometimes, doctors propose it, and sometimes the family initiates the request. On some occasions, there were no requests, and patients were put to death. In other cases, patients' requests were not durable and persistent as they need to be. The guidelines indicate a term too open to interpretation, like
unbearable suffering. Another reason for worrying is the large amount of unreported cases of euthanasia. All these troublesome aspects suggest to Cohen-Almagor a cautious attitude toward euthanasia. His answer is the proposal to restrict, as far as possible, the choice to die to the practice of physician-assisted suicide, that gives patients control over their lives until the last moment, and provides a further mechanism against abuses. Cohen-Almagor is ready to concede euthanasia just in two cases: «(1) the patient who asked the euthanasia is totally paralyzed, from head to toe, unable to move any muscles that could facilitate assisted suicide; (2) the patient took oral medication and the dying process is lasting for many ours» (17).

Cohen-Almagor's contribution to this part of discussion is extremely relevant, and I do not know of any other author who shows such a conscientious approach to the problem. The direct inquiry in Netherlands is precious. However, perhaps a comparative analysis may be useful. Kuhse provides comparative data between Netherlands and Australia. According to her data 3.5% of death in Australia (1996) are caused by lethal medication without the request of the patient, while in Netherlands (1995) this is 0.7%, less than in Australia. In Australia 22.5% of deaths are due to the withdrawal of treatment without the request of the patient, while in Netherlands the total amount of deaths due to withdrawal is 12.5% (18).

This, obviously, is not a reason to suspend caution in Netherlands, and not a refutation of Cohen-Almagor's conclusion related to the suspicion about euthanasia, and privileging physician-assisted suicide. Perhaps, this is the most reasonable attitude. However, the data indicated by Kuhse may suggest that a less restrictive, but regulated situation, is preferable to a more restrictive situation, because this one may represent a suitable ground for practices left to behavior less respectful of patient's will.

There is some continuity between the discussion of the Netherlands's case, and the discussion of the Oregon Death with Dignity Act. This is the other chapter that Cohen-Almagor dedicates to the practical verification of the regulation of choosing death. I will not discuss this chapter in detail, although I think that some parts of it are of notable relevance. First of all, there is the interesting consideration that speaks against some worries related to physician-assisted suicide. For example, the third report of the Oregon Death with Dignity Act indicates that twenty-seven patients have chosen death, where «fifteen of them were women; twelve men. Patients with a college education were more likely to choose physician-assisted suicide than those without a high-school education; patients with post baccalaureate education were more likely to choose physician-assisted suicide» (19). It seems that these data refute some fears that the permission of physician-assisted suicide will represent a danger for the discriminated population (20). The number of women that have chosen physician-assisted suicide is just a little higher than that of the men, while people of higher level education are more apt to choose this practice. Furthermore, the prominent consideration for the choice of physician-assisted suicide is the fear to lose autonomy, the decreased ability to participate in enjoyable activities, loss of the control of bodily functions, and being a burden to the loved ones. Although we must interpret this data with due caution, this seems to refute the attitude of those who think that adequate reduction of pain is a valid substitute for physician-assisted suicide.
6. In the remaining part of the book, Cohen-Almagor goes to his conclusions, where, among else, he offers some remarkable guidelines for a successful application of the dignified death policy. In the Appendix he offers a discussion about allocation of resources.

Cohen-Almagor’s book is a complete, interdisciplinary discussion of the question of the right to die with dignity. It may be of great interest to people coming from different experiences. Its language, and the methodology adopted by the author, makes possible to read it for a wide range of potential readers. An exceptional merit of the book is that it provides a balanced view that never renounces to pay due attention to human life, as well as to human dignity.

Note.


(4) J. David Velleman, *A Right to Self-Termination?*, “Ethics”, 1999. Cohen-Almagor in fact appeals to Kant’s concept of autonomy (pp. 3-4), but does not seem to face fully the specific meaning that this author attributes to “autonomy”.


the Debate, cit., pp. 91-112. The argument can, obviously, be extended to any other traditionally discriminated community.