Patients' Right to Die in Dignity and the Role of Their Beloved People

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I. Introduction

The aim of this paper[1] is to ponder the intricate issue of the right to die in dignity by focusing attention on the role of the patient's beloved people. I first consider some of the arguments advanced by Ronald Dworkin. Specific attention is given to what Dworkin terms 'critical interests' and to the notion of dignity. My discussion intends to refute Dworkin's contentions that a life that comprises only thin pleasures is not worth living, and that a person's past priorities when competent should be held decisive in determining whether to treat him or her upon becoming incompetent. We should continue to appraise a person's best interests over time to determine whether he or she is revoking previous statements and priorities. I proceed by an examination of three American court cases. The first case, *Saikewicz,* concerns a patient who had no family or other beloved people. I observe that this fact had a significant bearing on the court's ruling not to provide him treatment. The second case, *Spring,* involves a patient whose family wanted to withhold treatment from him. I argue that we should be cautious of incidents in which the best interests of the patient's beloved people come at the expense of the best interests of the patient. *Spring* is an example of such a case. The third case, *Gray*, serves as an example whereby the best interests of the patient coincide with the best interests of her beloved people. I conclude by arguing that consideration has to be given to the question of whether the patient's beloved people demonstrate a unified position in regard to the destiny of the patient. I should note that I prefer to speak of the patient's beloved people (or close-ones) than to speak of the family. The term 'the patient's beloved people' refers to persons who are emotionally closely related to the patient in concern. This close relation does not necessarily mean that only those who have biological and marital attachments should give their consent and advice. The opin-

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ion of a person who lived with the patient for the past five years without formal ties will be much more germane than the opinion of the patient's sister who lived abroad and used to see the patient only once in a while. The opinion of a very close friend with whom the patient used to confide and consult is much more important than the opinion of his or her father who broke relations with the patient.

Some further clarifications have to be made concerning the scope of the analysis and the terms 'respect' and 'concern', which are in the foci of the discussion. First, my point of reference is limited to liberal societies. Other societies do not place emphasis on the individual and may apply different rules and codes of behaviour from those which I take for granted as underlying liberal democracies, i.e., respect and concern for others and not harming others. I believe that there are some basic universal needs that all people wish to secure such as food, raiment and shelter. But we cannot speak of universal values that underlie all societies. Thus my concern is with liberal democracies which perceive human beings as ends and which respect autonomy and variety.

Moreover, in a liberal society basic health is seen as one of the necessary conditions for the exercise of personal autonomy. Liberal societies acknowledge that individuals have a right to health care. The prevalent assumption is that this right generates an obligation or duty for the state to ensure that adequate health care is provided and that there should be equal access to whatever health-care resources are provided out of the public purse. The state has no obligation to provide a health-care system itself, but to ensure that such a system is provided. Basic health-care is now recognized as a 'public good' rather than a 'private good' that one is expected to buy for oneself.[2] As the Constitution of the World Health Organization put it: "The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition".[3]

The further clarification relates to the terms 'respect' and 'concern'. Respect for a person means conceiving of the other as an end rather than as a means to something. As Immanuel Kant explains, rational beings are called persons inasmuch as their nature alone indicates that they are ends in themselves, i.e., as something which is not to be used merely as a means. Hence a limit is imposed on all arbitrary use of such beings, which are recognized as objects of respect. Persons are, therefore, not merely subjective ends, whose existence as an effect of our actions has a value for us; but such beings are objective ends, i.e., exist as ends in themselves.

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2 *Max Charlesworth,* Bioethics in a Liberal Society, Cambridge: Cambridge University Press, 1993, p. 108. For further discussion on the duties of the liberal state in maintaining the health of its citizens see *Troyen A. Brennan,* Just Doctoring, Berkeley: University of California Press, 1991, esp. chaps. 3, 4, 8, 9.

3 Adopted by the *International Health Conference* held in New York from 19 June to 22 July 1946 and signed by the representatives of 61 States, in: The United Nations and Population: Major Resolutions and Instruments, New York: Dobbs Ferry, 1974, p. 204.

Such an end, Kant maintains, "is one for which there can be substituted no other end to which such beings should serve merely as means, for otherwise nothing at all of absolute value would be found anywhere".[4]

According to Kant, to respect a person is to treat him or her as a human being, as an autonomous being who is acting upon recognition of the moral law. The assumption is that beings are moral and Kant's demand is that people act in accordance with the Categorical Imperative. The Categorical Imperative refers to the will itself, not to anything that may be achieved by the causality of the will. Morality, according to Kant, cannot be regarded as a set of rules which prescribe the means necessary to the achievement of a given end, whether the end be general happiness, human perfection, self-realization, or anything else. Moral rules must be obeyed without consideration of the consequences that will follow from doing or refraining from doing something. Moral rules guide our actions and are observed as a precondition for compatibility with the actions of other people.[5]

Kant does not speak of the process of decision making. Unlike him, I wish to lay emphasis on the very process of reaching a decision. In this process we exercise our faculties, using concepts, categories, principles, norms and to some degree (whether we like it or cannot help it) our emotions. We construct and de-construct realities, converse and exchange ideas, listen to the advice of others and share our opinions with people we appreciate. At least on matters we conceive to be of importance we strive to reach the right decision. As long as people accept the two basic principles that underlie liberal society, respect for others and not harming others, we accord others respect when we respect their right to make decisions, because they are *their* decisions, regardless of our opinions of them. We simply assume that each person holds his or her own course of life as intrinsically valuable, at least for himself or herself, and in most cases we respect the individual's reasoning.[6] We should give equal consideration to the interests of others and should grant equal respect to their life projects as long as these projects do not deliberately undermine the interests of others by interfering in a disrespectful manner. In this context, may I further refer to the writings of John Rawls and Ronald Dworkin. Rawls asserts that "the public culture of a democratic society" is committed to seeking forms of social cooperation that can be pursued on a basis of mutual

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4 *Immanuel Kant,* Foundations of the Metaphysics of Morals, trans: Lewis White Beck, Indianapolis, Indiana: Bobbs-Merrill Educational Publishers, 1969, Second section, esp. pp. 52-53.

5 The postulate, "You ought never to tell lies" is an example of the Categorical Imperative. There is no way of evading the command or the moral requirement of practical reason which it expresses, for no end is mentioned and there is therefore no end which can be given up. For further discussion see *J. Kemp,* The Philosophy of Kant, Oxford: Oxford University Press, 1979, p. 58.

6 On some issues the liberal state adopts a paternal approach that overrides individual decision making. Thus, for instance, to protect our security the liberal state requires us to fasten seat-belts when we travel by car and to wear crash helmets when riding motorcycles.

respect between free and equal persons.[7] And Ronald Dworkin regards the entire political morality as resting on the single fundamental background right of everyone to human dignity and to equal concern and respect.[8]

The notion of 'concern' signals the value of well-being: we ought to show equal concern for each individual's good, to acknowledge that human beings are not only rational creators but also emotional creatures. Treating people with concern means to treat them with empathy, to view people as human beings who may be furious and frustrated, who are capable of smiling and crying, of careful decision making and of impulsive reactions. By 'concern' is not meant anything so demanding as giving equal weight, utilitarian fashion, to the welfare of a stranger as a person does to the welfare of his or her own children.[9] Instead, it is giving equal weight to a person's life and autonomy.

Let me now proceed by introducing some of Ronald Dworkin's contentions. These contentions will serve as a spring-board for exploring the complexities involved in the debate on the right to die in dignity and more specifically on the role of the family and the patient's loved-ones in deciding the future of patients, especially of deformed and unconscious patients.

II. Dworkin's Contentions

In his most recent book, *Life's Dominion,* Dworkin contemplates a case where a person named Margo had executed a formal document directing that if she should develop Alzheimer's disease or any other life-threatening disease she should be killed as soon and as painlessly as possible. Dworkin asks whether autonomy requires that her wishes be respected now when she is ill even though she seems perfectly happy with her dog-eared mysteries, the single painting she repaints, and her peanut-butter and jelly-jam sandwiches. In such a case, an apparent contradiction seems to exist between past and present wishes, between past and present autonomy. Dworkin endorses respecting Margo's past wishes, arguing that a competent person making a living will providing for her treatment if she becomes demented is making the kind of judgment that autonomy, on the integrity view, most respects: a judgment about the overall shape of the kind of life she wants to have

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7 *John Rawls,* "Liberty, Equality, and Law", in: Sterling M. McMurrin, ed: Tanner Lectures on Human Values, Cambridge, England: Cambridge University Press, 1987, pp. 1-87, sect. 3; "Justice as Fairness: Political not Metaphysical", 14 Philosophy & Public Affairs, No. 3 (1985), 223-251.

8 By background rights Dworkin means rights that provide a justification for political decisions by society in the abstract, without connecting them to any specific political institution. See *R. M. Dworkin,* Taking Rights Seriously, London: Duckworth, 1977, pp. 150-183, 266-278; "Liberalism", in: A Matter of Principle, Oxford: Clarendon Press, 1985, pp. 181-204.

9 Cf. *James Griffin,* Well Being, Oxford: Clarendon Press, 1986, chap. IX.

led.[10] This is a central point in Dworkin's argument and I will criticize it later on. But first I wish to introduce Dworkin's other themes.

Dworkin explains that most of us think it is important to achieve something in our lives. We all have ambitions. We all want a decent life upon which we could look with pride and satisfaction. We have two kinds of interests: we want pleasure and enjoyment in virtue of desires and ambitions. We also want to live a worthwhile life. That is, we look at our lives as a kind of assignment, a mission. The first kind of interests is called *experiential;* the second *critical* interests.[11]

In considering the Margo case, Dworkin implies that a life which does not include critical interests is a poor life, in terms of its quality. What we seek is not just any form of life but rather life in earnest. This reasoning brings Dworkin to conclude that a life that includes peanut-butter-and-jelly sandwiches and similar trivial things is not worth living. Eating these sandwiches cannot bring a person to consider his or her life as a kind of assignment, as a mission.

Dworkin further emphasizes the notion of dignity. Dignity is the central aspect of the intrinsic importance of human life.[12] A person's right to be treated with dignity is the right that others acknowledge his or her critical interests: that they recognize that he or she has a moral standing, and that it is intrinsically, objectively important how his or her life goes. Bearing this view in mind I ask you to consider the following issue. Most of us have a critical interest in having a family. This critical interest is connected to our convictions about the intrinsic value of our own lives. We are concerned with how people look at us. We all have an interest in the kind of memories that will survive after death. We do not want to be remembered as people who were dependent on others, unable to perform the simplest actions. Moreover, most of us care about our families and we would not like to cause them suffering. Sometimes patients are in agony not only because of the disease that causes them pain but also from the bare knowledge that their anguish torments their families. It is among the patient's interests to have the memories of his or her loved-ones filled predominantly with thoughts about his or her past vitality, rather than with his or her present condition. Thus, many are inclined to minimize the burden that their illness imposes on others. Dworkin writes that many people do not want to be remembered living in circumstances conceived by them as degrading. At least part of what people fear about dependence is its impact not on those responsible for their care but on their own dignity. Dworkin contends that some people are horrified that their death might express the idea which they detest as a perversion: that mere biological life – just hanging on – has independent value.[13]

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10 *Ronald Dworkin,* Life's Dominion, New York: Knopf, 1993, pp. 226-233.

11 *Dworkin* (op.cit. fn. 10), pp. 201-213.

12 *Dworkin* (op.cit. fn. 10), p. 236.

13 *Dworkin* (op.cit. fn. 10), pp. 210, 212.

Dworkin maintains that when we think of dignity, it is *not* just life in *any* form that is important. Anyone who believes in the sanctity of human life believes that once a human life has begun it matters, intrinsically, that that life goes well, that the investment it represents be realized rather than frustrated.[14] Dworkin's contention comes close to that of a recent British court's decision. In deciding the best interests of Post-Coma Unawareness (PCU) patients, the court counted among the relevant considerations the avoidance of invasive and undignified procedures, which would have an adverse effect upon the way the patients concerned would be remembered by their loved ones.[15] I will reflect on Dworkin's contentions anon, but first let me say few words on PCU patients.

The case of PCU patients is one of the difficult cases bioethics is being confronted with in this era. Current technology enables people to remain alive in circumstances that at least some of them earlier dreaded. Due to speedy evacuation of patients with brain injuries, well-equipped medical centres, early diagnosis by computerized tomography, advanced surgical methods, and finer intensive care and post-operative care, technology has increased the number of survivors following the acute phase of trauma, strokes or heart failures. Many of these survivors remain in a state of deep sleep.

The term PCU is used in referring to these patients who are in the twilight zone between life and death. PCU patients suffer from a serious damage that is inflicted on their brain cerebrum. They are unconscious, unresponsive to external stimuli, but capable of independent spontaneous respiration and a regular heart beat. It is the combination of reflexive activity in the absence of sensation or conscious activity that characterizes the PCU situation.

Injuries inflicted on the brain cerebrum are not the same as injuries inflicted on the brain stem. Current medicine declares as dead any person whose brain stem activity is absent. This is not the case when the brain cerebrum is damaged. The brain stem controls basic reflexes, including breathing, heart activity, the sleep/awake cycle, reflexive activity in the upper and lower extremities, some swallowing motions and eye movements.[16] The brain cerebrum controls sensations, volun-

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[14] *Dworkin* (op.cit. fn. 10), p. 215.

[15] Cf. *Airedale NHS v. Bland* [1993] 1 All ER 821, at 870.

[16] Responses to confirmatory tests to examine whether the brain stem is injured include: fixed pupils with no response to light; corneal reflex absent; vestibulo-ocular reflexes absent; no motor responses elicited within the cranial nerve distribution; no gag reflex or response to bronchial stimulation by a suction catheter passed down the trachea; no respiratory movements when the patient is disconnected from the mechanical ventilator for long enough to ensure that the arterial CO_2 rises above the threshold for stimulating respiration. Cf. *E. McClatchey,* "Some Aspects of Euthanasia from the Point of View of a Family Doctor", in: Amnon Carmi, ed: Euthanasia, Berlin: Springer-Verlag, 1984, pp. 103-109, at 106. See also *Alan C. Hoffman, J.D. / Mark X. VanCura,* "The Brain Criteria", in: Andre de Vries / Amnon Carmi, eds: The Dying Human, Ramat-Gan: Turtledove, 1979, pp. 325-343, at 337-338; and *Coordinating Council on Life-Sustaining Medical Treatment Decision Making by the Courts,*

tary and conscious activities. Unlike patients whose brain stem is injured, PCU patients may show some progress in their situation and the possibility of awakening is present. I should further clarify that I prefer the term 'PCU' to the widely used term 'PVS' (Persistent Vegetative State). This is because the term 'vegetative' strikes me as dehumanizing the patients in concern.

Dworkin has no qualms referring to some patients as vegetables.[17] He assumes that harm is being done when a patient is living on as a vegetable.[18] As I related earlier, in his criticism of the *Cruzan* ruling Dworkin asserts that if a person (Margo) has stated while in good health, and after careful deliberation, that she would not care to have her life extended if she becomes demented, able to enjoy only trivial things such as peanut-butter-and-jelly sandwiches, that declaration should be rendered as determinative and be respected even if, when the time comes, she seems to be happy enough and finds some value in her demented state.[19]

Contrary to Dworkin's arguments, my contention is that a thin pleasure of the kind of peanut-butter and jelly-jam *is* worth having. Evidence shows that many people who reach the stage of permanent dementia and live non-autonomous life nevertheless cling to life and find pleasure in things that had no importance for them in the past. Their present order of priorities should win over past considerations. Dworkin seems to think that one's directives are predetermined and unchangeable, but this is not necessarily the case. We are not able to know how our lives will look when we are about to die. We are not able to say that values and priorities that are important to us now will be as important to us until the very last day. The notion of an unchangeable, unified personality is doubtful. People do change and these changes may become meaningful to us in circumstances that we cannot envisage. The very idea of autonomy reflects our ability and want to construct and reshape realities, to re-evaluate values and ideas, to renounce old beliefs and to accommodate ourselves to new situations. Dworkin assumes that people, as rational agents, may have certain attitudes regarding dementia and decide beforehand that some forms of life are repugnant, meaningless, not worth living. People try to assess how their situation might look in the future and decide on their destiny according to the data they have on the demented state. However, people are not only thinking creatures. Not all factors could be grasped by our rational faculties. Not all data could be digested by applying reason and judgment. Sometimes we do things we could not imagine doing. Sometimes people act in accordance with their sentiments, not brain. Sometimes people are pushed to do something by their instincts, their impulses, factors that they find difficult to explain in rational terms.

Guidelines for State Court Decision Making in Authorizing or Withholding Life-Sustaining Medical Treatment, Williamsburg, Virginia: The National Center for State Courts, 1991.

17 See, for instance, *Dworkin* (op.cit. fn. 10), at 180, 230-232.

18 *Dworkin* (op.cit. fn. 10), p. 232.

19 *Dworkin* (op.cit. fn. 10), chap. 8.

On some occasions people are overpowered, overwhelmed by the reality they confront. They accommodate themselves to situations imposed on them.

To conclude this critical point, the assessment process does not necessarily stop in the demented stage, as Dworkin would like to suggest. We should acknowledge that a person's priorities are not always fixed, and therefore we should not renounce the idea of having the ability to change them. People are *not* prophets. We can appraise possibilities upon evidence, data, experience, but we cannot know with absolute certainty that these assessments would prove to be true for us. Most people are willing to make a commitment which they think would last a lifetime, e.g., marriage, and many of these people prove to be wrong and at a later point in their lives ask for a divorce. One may try to imagine what he or she would feel in the future upon reaching a certain condition, but on many issues one's imagination does not suffice to fully comprehend the future new reality. A parallel example may be the thought of becoming a parent and actually being a parent. One may think that one understands what becoming a parent entails, what it involves. One may try to exercise one's cognitive capacities to put oneself in the position of a parent. But one would be able to really grasp the sense of obligation, of love and affection involved in becoming a parent *only* upon becoming a parent. This is because we are not merely thinking creators, but also passionate, emotional beings. We love and like to be loved, to give and to share, and these virtues could be appreciated only upon experiencing them. Applying cognitive faculties would be a good start to fathom what is involved in being a parent, but having experience is a different matter. The same reasoning holds for the thought of becoming demented to be distinguished from the actual suffering of dementia.

In support I may add the words of two Israeli doctors, Dr. Nachman Wilensky, Director of Lichtenstaedter Hospital for chronic patients, and Dr. Zev Susak, General Director of Lowenstein Rehabilitation Centre, who contend that people have an impulse to cling to life which is stronger than any pain or suffering they are going through. We tend to emphasize the integrity of the body, autonomy, privacy and dignity. The question is whether these things are as important to the incompetent person as they are to the competent.

In coming to decide the fate of incompetent patients such as those who are in PCU, consideration has to be given to whether the patient's condition is irreversible, whether a chance exists for rehabilitation of some constitutive, vital elements of human life, whether the patient expressed his or her desire to die upon reaching a certain state of living, and also whether we feel that the patient's current interests are similar to the interests he or she expressed in the past. These preconditions affirm values that liberals so much appreciate, i.e., autonomy and respect for others. Other relevant considerations include the opinions of physicians and of the patient's family and his or her beloved people.

In the following section I wish to focus attention on one of the pertinent considerations that we should bear in mind when coming to decide the patient's destiny.

I wish to consider the role of the patient's beloved people by contemplating relevant scenarios and examining exemplifying court decisions.

III. Best Interests of Whom? The Patient's Wants and his or her Beloved-ones' Commitments

Reflect on the following instance. Sheila is gravely ill. She suffers from a progressive dementia and the attending physician is not able to provide her with treatment that may halt the progress of the disease. The physician is able only to relieve her pain. Sheila's condition continues to deteriorate and she is unable to perform the actions she had done in the past. In Dworkin's terminology, Sheila has reached a stage where she is incapable of actively advancing most of her critical interests. She is no longer able to pursue her career, to practice her religion the way she did in the past, and to maintain her friendship with most people she knows. Furthermore, Sheila's range of experiential interests becomes extremely limited. She is incapable of playing the guitar, walking, eating as she used to, or visiting the theatre. But Sheila has a family and she shows signs that her critical interest in having a family and enjoying its company is still present. Sheila feels the love of her family. She appreciates it and enjoys the constant company and support of her parents and her other close relatives. From time to time she expresses her feelings by a smile or a sound.

Now, in the past Sheila has voiced a critical interest in not being sustained upon reaching such a stage in life. When competent, Sheila did not think that mere minimal communication with her family could constitute a worthwhile life. But her current behaviour gives members of her family (and other people who care about her) the impression that their company in itself makes Sheila's life worthwhile. Dworkin does not consider the possibility of a conflict between two critical interests, one indicated in the past, the other alluded to in the present. He may not see Sheila's present condition as a life which can be considered as an assignment, as a mission. Nevertheless, as far as people around Sheila can judge, she finds some value in her life. Should we respect Sheila's critical interest which was voiced in the past in not having her life sustained upon reaching such a condition, or should we respect the other critical interest which concerns Sheila's family and their mutual love? Which critical interest should have precedence over the other? Moreover, are the *family's* critical interests of any relevance? That is, in a case where physicians support discontinuation of life and the patient's close-ones object, are we to respect their critical interest in maintaining the patient's life?

The described situation is *not* one in which the family makes Sheila feel that she constitutes a burden. The family does not exert social pressure on Sheila to die. The opposite is the case. If Sheila were to feel that she constituted a burden on her family and on other people she loves; if she were to feel that her family would rather see her dead, then Sheila might have decided to opt for dying. But if those

who care for Sheila feel that her candle is still dripping; that, on balance, her life is still worth living, her pain is being controlled and her smiles reassure their support, then Sheila would have no social incentive to terminate her life before *she* feels her life were to become meaningless.[20]

Some explanatory words should be said regarding this sort of family's commitment. In the described scenario, members of Sheila's family practically live their lives around her bed. Obviously, their commitment places some restrictions on their variety of options for action. But they do not view these restrictions as impediments on their freedom or autonomy. Members of Sheila's family and others who care for her willingly accept sacrifices, thereby expressing themselves, their sense of giving, of sharing, of love and any other affective notion that is valuable for defining their world as autonomous agents. Many of us may have an interest in giving to others because the act of giving, and the recognition that we make others happy, contributes to our satisfaction, making us feel more humane, with a personality that has been bettered. Restricting ourselves in such cases does not go against our interests. Instead, it is conducive to promoting our position through the effort of contributing to others. We all have an interest in promoting egoistic motives, but for similar or other reasons we also have an interest in furthering altruistic notions. Thus we are willing to take on sacrifices and restraints. Comforting a severely ill patient does not necessarily have to be regarded as an imposition. Many would prefer this demanding sacrifice to the alternative.

A caveat has to be made in this context. Not all families are like Sheila's family. Sometimes partisan motives (financial considerations, rivalries within the family, etc.) may influence the family's position. It is the task of social workers to verify that the family is, indeed, close to the patient. Physicians are preoccupied with other business and cannot spend time on inspecting the nature of relationships between the patient and his or her family. But physicians and social workers should not take for granted that the family truly cares for the patient in concern. Sometimes other people (friends, colleagues, past and present lovers) care more for the patient than the family. Someone has to verify that genuine interests are involved and, I submit, that person has to be the social worker assigned to the patient. I am not saying that the social worker should take detective courses or listen-in on confidential discussions. What I suggest is to have open and frank discussions with all those who claim to have close relationships with the patient. It is better to have these conversations than to leave the framework of relationships unexamined.

Furthermore, even if we are convinced of the family's commitment to the patient we should not in all cases see the family's position as determinative. Sometimes

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[20] The factors of pain and suffering (physical, psychological and spiritual) are of crucial importance. If it became impossible to control Sheila's pain and suffering then she probably will not be able to enjoy the company and affection of her family as she does. Sheila's family, in turn, may come to the conclusion that, on balance, it is in Sheila's best interest to depart life.

the family is incapable of rational decision-making. Sometimes the strain on the family is too severe for its members to cope. Evidence gathered in Israel shows that the closest ties are those between the patient and his or her parents. Thus whenever possible, it is preferable to ask for the opinion of not only the patient's spouse (when he or she has one), but also other members of the family, especially the parents. What I have in mind is a council of all those who step forward claiming to have close association with the patient, freely and openly discussing the future of their loved-one, bringing forward all considerations for and against the continuation of life. This gathering will take place after physicians have expressed the opinion that available medicine cannot cure the patient in concern, that his or her situation will deteriorate, and that no hope for recovery is present.

Let me further consider the role of the patient's close-ones through a discussion of three American court cases. American law recognizes as valid an act of consent to treatment of an incompetent person given in a traditional manner by the family, next of kin, or a guardian.[21] The President's Commission for the Study of Ethical Problems and Biomedical and Behavioral Research concluded in its resolutions that "the family is generally most concerned about the good of the patient"; that the family "will also usually be most knowledgeable about the patient's goals, preferences and values"; and that the family "deserves recognition as an important social unit that ought to be treated, within limits, as a responsible decision-maker in matters that intimately affect its members".[22]

The first case I examine, *Saikewicz,* involves a retarded patient who had no close-one to care for him. I argue that the absence of family and beloved people was of significance in deciding not to administer chemotherapy and let him die. In the second case, *Spring,* the family played a crucial role in convincing the court that the patient should not continue receiving dialysis treatments. Here I voice doubts as to whether that decision truly respected the best interest of the patient. This is a case where the best interests of the patient conflicted with the best interests of the family. The third case, *Gray,* serves as an example for what seems to be a positive role on the part of the family to let a patient die in dignity when no apparent contradiction exists between the patient's interests and the interests of her family.

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21 Cf. *John F. Kennedy Memorial Hospital Inc. v. Bludworth*, 452 So 2d 921, (Fla 1984), at 926; *In re Jobes*, 108 NJ 394, 529 A 2d 434, (NJ 1987), at 444-447; *In re L.H.R.*, 321 SE 2d 716, (Ga 1984), at 723.

22 *The President's Commission for the Study of Ethical Problems and Biomedical and Behavioral Research,* Deciding to Forego Life-Sustaining Treatment (1983), p. 28.

IV. Court Cases

1. Saikewicz[23]

The *Saikewicz* case involves a sixty-seven-year-old patient who had been severely retarded since birth, whose I.Q. was of a ten-year-old and his mental age of approximately two years and eight months. He had never learned to talk and never had the capacity to form a view about his medical care. Mr. Saikewicz suffered from acute myeloblastic monocytic leukemia, for which chemotherapy was the only possible treatment. Despite the fact that most people in Mr. Saikewicz's position elect to suffer the side-effects of chemotherapy rather than to allow their leukemia to run its natural course, a guardian ad litem recommended withholding the treatment, and his recommendation was accepted by the Massachusetts Supreme Judicial Court.

Justice Liacos, who delivered the opinion of the court, considered two factors in favour of administering chemotherapy: the fact that most people elect chemotherapy, and the chance of a longer life. These considerations were balanced against factors weighing against administration of chemotherapy. The court asserted that evidence that most people choose to accept the rigors of chemotherapy "has no direct bearing on the likely choice that Joseph Saikewicz would have made" (at 430). The guardian ad litem explained that if Saikewicz were to be treated with toxic drugs he would be involuntarily immersed in a state of painful suffering, the reason for which he would never understand (at 430).

In addition to these two factors, the certainty that treatment would cause immediate suffering and Saikewicz's inability to cooperate with the treatment, the court weighed four further factors against providing chemotherapy. These were: Saikewicz's age (persons over the age of sixty have more difficulty tolerating chemotherapy and the treatment is likely to be less successful than in younger patients); the probable side effects of treatment; the low chance of producing remission; and the doctors' opinion that a decision to allow the disease to run its natural course would not result in pain for the patient, and death would probably come without discomfort.

The *Saikewicz* ruling is highly problematic. It is a case were paternalism was disguised as acting on the premise of the "autonomy principle". The court spoke of a "right of privacy" for incompetent individuals who cannot comprehend their situation and used the substituted-judgment doctrine to interfere with their privacy. The court recognized a general right in all persons to refuse medical treatment in appropriate circumstances without knowing, and without having the ability to know, what Mr. Saikewicz would have wanted. The court for its own reasons chose to stress this general right, ignoring the fact that most people choose to accept the rigors of chemotherapy, by saying that this "has no direct bearing on the likely

[23] *Superintendent of Belchertown v. Saikewicz*, Mass. 370 N.E.2d 417 (1977).

choice that Joseph Saikewicz would have made". The court contended that the recognition of that right to refuse medical treatment "must extend to the case of an incompetent, as well as competent, patient because the value of human dignity extends to both" (at 427). This has come to mean that the court should make that decision for incompetent wards because they themselves are unable to make rational decisions and decide their own fate. The court said that "the State must recognize the dignity and worth of such a person and afford to that person the same panoply of rights and choices it recognizes in competent persons" (at 428). Yet many would regard the *continuation* of life rather than the discontinuation of life as better protecting the dignity of incompetent persons.

The following statement encompasses many of the problems involved in the *Saikewicz* ruling. The court held that it believed the guardian ad litem should attempt "to ascertain the incompetent person's actual interests and preferences" and the decision should be that which "would be made by the incompetent person, if that person were competent, but taking into account the present and future incompetency of the individual as one of the factors which would necessarily enter into the decision-making process of the competent person" (at 431). It is very difficult to understand what the court meant by this mumbo jumbo formulation. Mr. Saikewicz was unable to express his preferences in the past. There is no plausible way to reconstruct his preferences from statements made at some earlier time, as there sometimes is for patients, as in the widely known cases of *Quinlan* and *Cruzan*.[24] How can the court "ascertain the incompetent person's actual interests and preferences"? Furthermore, what is the purpose of trying to assess which decision "would be made by the incompetent person, if that person were competent"? The court did not really believe in this exercise, for Justice Liacos maintained that we should also take into account "the present and future incompetency of the individual as one of the factors which would necessarily enter into the decision-making process of the competent person". Justice Liacos had to maintain this to rule as he did even though most patients in Mr. Saikewicz's situation will elect to go on with chemotherapy. The self-deception finds expression in the concluding remarks, "that the patient's right to privacy and self-determination is entitled to enforcement" (at 435). This comes to mean that Mr. Saikewicz is entitled not to receive chemotherapy, and to die.

One crucial factor that is usually present in cases of the right to die in dignity that is totally absent from this case involves the family. Justice Liacos mentioned in his ruling the guardian ad litem. No word was said about Mr. Saikewicz's family, which brings us to the conclusion that he had no one who loved and cared for him. If Mr. Saikewicz had had a family and the family had requested chemotherapy treatment, the case would probably not have reached the court. The absence of

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24 *In re Quinlan* 70 N.J. 10, 355 A.2d 647 (1976); *Nancy Cruzan v. Robert Harmon* 760 S.W.2d 408 (1988); *Nancy Cruzan v. Director, Missouri Department of Health* 497 U.S. 261 (1990), 110 S. Ct. 2841. The *Gray* decision is another example to be discussed later on.

family decided, to a large extent, Mr. Saikewicz's fate. We can speculate that a caring family might have liked to enjoy Saikewicz's company for as long as possible and might have rejected the factors the court emphasized in deciding against treatment. Vulnerable, unwanted, abandoned, and may I say inconvenient classes of people may have to suffer the consequences of the *Saikewicz* ruling.[25]

The family plays a crucial role in the two other cases which I would like to ponder. In the *Spring* case, the family decided to terminate hemodialysis treatments of the patient and the court concurred. I can understand the result, but the case raises doubts as to whether the role of the family should be considered most crucial. The further case, *Gray v. Romeo,* is, to my mind, a clear case, and I am using it to show when the right to die in dignity should be respected.

2. *Spring*[26]

The case involved an incompetent person whose wife petitioned the court for an order that hemodialysis treatments, which were sustaining the life of the ward, be terminated. The court held that where it was established that 1) it would be the wish of the incompetent ward, if competent, to discontinue his or her dialysis treatments; 2) the ward's life was essentially behind him or her; 3) he or she was not a suitable candidate for a kidney transplant; 4) his or her remaining days were to be spent in an irreversible state of dementia; and 5) the physician treating the ward supported the view of the ward's family that further treatment was inappropriate, then the state's general interest in the preservation of life was not sufficient to warrant intervention in the treatment decision.

Justice Armstrong, who delivered the opinion of the court, reviewed at a considerable length the relationships between Earl N. Spring, the patient, and his family (at 495, 499). It was said that Mr. Spring was married to his wife Blanche for more than fifty-five years. Their son Robert had lived for more than fifteen years across the street from his parents' house and had visited them virtually every day during that time. Mrs. Spring and Robert Spring had been active participants in caring for the patient's needs since the onset of his precipitous physical and mental deterioration. The court was convinced that this was a case of a close-knit family unit, with

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25 In her criticism of the *Saikewicz* decision Lynn D. Wardle writes that the "consent" of many incompetent individuals is nothing more than a shabby legal fiction, like the fiction of "separate but equal" which was adopted by the United States Supreme Court in *Plessy v. Ferguson* 163 U.S. 537 (1896) and which for decades was the justification for racial discrimination as officially accepted in the United States until its overruling nearly sixty years later in *Brown v. Board of Education* 347 U.S. 483, 495 (1954). Cf. *Lynn D. Wardle,* "Sanctioned Assisted Suicide: 'Separate But Equal' Treatment for the 'New Illegitimates'", 3 Issues in Law and Medicine, No. 3 (Winter 1987), 245-265, at 262. For further discussion see *Ira Mark Ellman,* "Can Others Exercise an Incapacitated Patient's Right to Die?", 20 The Hastings Center Report, No. 1 (January / February 1990), 47-50.

26 In the Matter of *Spring,* Mass.App. 399 N.E.2d 493 (1979).

a long history of mutual love, concern and support. In a footnote (at 499) Justice Armstrong addressed the issue of financial considerations and said that such considerations were not involved because the dialysis treatments were paid for by social security.

Justice Armstrong also emphasized the burden which Mr. Spring had imposed upon his family after he developed kidney failure. His wife and son had to transport him three times a week to a private kidney centre in another town for dialysis treatment (at 495, 496, 500). Those treatments last five hours each (at 495). Furthermore, Mr. Spring's physical deterioration was accompanied with mental disorientation. His behaviour at home became somewhat belligerent and destructive, and he could no longer care for himself. Mr. Spring was diagnosed as having "chronic organic brain syndrome". Later Mr. Spring's mental deterioration had progressed to the point where he was unable to recognize his wife and son.

The crisis in the family had increased when Mrs. Spring suffered a stroke, temporarily losing her ability to speak. Robert Spring attributed the stroke to strain and exhaustion resulting from his father's behaviour and condition. After some six months, Mrs. Spring became well enough to be discharged from the hospital to her home. But she could no longer take care of her husband. She needed to devote all her energies to taking care of herself.

At that time Mr. Spring was in a nursing home. His disruptive behaviour was controlled through heavy sedation. He had occasionally kicked nurses, resisted transportation for dialysis, and pulled the dialysis tubing from his body (at 496). Mrs. Spring and Robert Spring expressed the view that if Mr. Spring were competent to voice his opinion, he would wish to have dialysis discontinued, although that would result in his death. That view did not rest on any expression of such an intention by the patient (at 498). Nevertheless, the court accepted the view of the patient's family. The court held that in circumstances of a close-knit family unit "the decision of the family, particularly where that decision is in accord with the recommendation of the attending physician [as is the case here], is of particular importance, both as evidence of the decision the patient himself would make in the circumstances and, at a later stage of analysis, as a factor lending added weight to the patient's interest in privacy and personal dignity in the face of any countervailing State interests" (at 499).

While in the *Saikewicz* case I argued that the absence of the family was one of the reasons why the court refused to order chemotherapy to sustain life, in this case it seems that the presence of the patient's family brought upon Mr. Spring the same result that was imposed on Mr. Saikewicz. However, while I strongly protest against the *Saikewicz* ruling and think the decision was wrong, I cannot hold the same for *Spring*.[27] This case raises a vexatious moral dilemma.

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27 If the conditions were to be different, a possible and preferable solution would be to relieve the Spring family from its responsibilities to Earl Spring by providing for him private nursing care.

While the result might seem to be disturbing, namely the outweighing of the countervailing State interest in the preservation of life, I can nevertheless understand it. In a sense the court had to balance the life of Mr. Spring against the life of Mrs. Spring. The situation as it developed had reached the point where one life went against the other, where one life came at the expense of the other. The court gave more consideration to the one who had a better chance to live a meaningful life. In this crude situation of a zero sum game, the court had to weigh all interests and reached the decision that the best alternative was to cease treatment for Mr. Spring. The court held:

"When the treatments were initiated, it was hoped that they would restore the ward's ability to enjoy a relatively normal existence, subject of course to the burden of lengthy and uncomfortable treatments far from home three times a week, but otherwise permitting him the pleasure of life with his family in familiar and comfortable surroundings. Unfortunately, this hope did not and cannot materialize; he is, and must remain, institutionalized, heavily sedated to restrain his hostile impulses, uncooperative towards his arduous maintenance program, insensible of his family and his situation. There now obtains a very different set of circumstances from those in which the decision to undertake dialysis was made" (at 499-500).

From the data as described by the court one can infer that the Spring family was, indeed, a close-knit family unit. One gets the impression that Mrs. Spring and Robert Spring loved Earl Spring. They found it terribly distressing to see the man they had shared their lives with for so many years fading away, failing to recognize them, acting brutally and becoming a different person. They could not cope with this situation. The appeal to the court was made also in order to keep their own sanity, their own lives. It seems that Mrs. Spring and Robert Spring sincerely thought that by withholding treatment from him they preserved his dignity. The question remains whether Mr. Spring himself would have preferred to die. I stress that Mr. Spring himself gave no indication, while competent, that he would rather die.

From this case you may infer why I previously argued that even if we are convinced of the family's commitment to the patient, we should not see the family's position as obligatory in all cases. The family's role should be held as a prominent consideration, but we should take into account first and foremost the best interests of the patient. The family is not necessarily capable of rational decision making, and even if it is, its interests are not necessarily identical to the interest of the patient. Thus, against John Hardwig's contention that we should build our theory of medical ethics on the presumption of equality – the interests of patients and family members are morally to be weighed equally – my argument is that we should think in terms of hierarchy.[28] In some instances the patient's interests in the maintenance

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[28] Cf. *John Hardwig,* "What About the Family?", 20 The Hastings Center Report, No. 2 (March / April 1990), 5-10. For further discussion on the role of the family see *Joseph Richman,* "Sanctioned Assisting Suicide: Impact on Family Relations", 3 Issues in Law and

of treatment and in a longer life may well be strong enough to outweigh the conflicting interests of other members of the family.

Let me move on to discuss the third and last case which, to my mind, poses no difficulty and exhibits familial decision making on the right to die in dignity that has to be cherished and respected as the court, indeed, ruled.

3. Gray v. Romeo[29]

This case involves Mrs. Marcia Gray who was diagnosed as a PCU patient. Her family, including her husband, her two children, her mother and her sister-in-law requested that her attending physician order that feeding be stopped and that Marcia Gray be permitted to die. Mrs. Gray's family was convinced that it would be her desire not to be sustained with artificial measures if her life were otherwise hopeless. The family relied on statements made by Mrs. Gray explicitly asking not to keep her alive by artificial means should she ever be in PCU.

The court held that a person has a paramount right to control the disposition to be made of his or her body even if the decision results in that person's death. Marcia Gray's right to privacy encompasses the right to refuse life-sustaining medical treatment (at 586). The court was convinced by the evidence that Mrs. Gray, if competent, would refuse treatment. Her right to self-determination outweighed competing governmental interests that include the preservation of life, the prevention of suicide, the protection of innocent third parties, and the integrity of medical ethics.

The court gave much emphasis to the role of the family. Justice Boyle, who delivered the opinion of the court, wrote that "the depth, quality, and reasoning of the family's prediction of Marcia Gray's intent is impressive. The family speaks with one voice and no apparent conflict of interest exists" (at 588).[30]

This case, to my mind, raises no difficulties. It is an example of a family council, freely and openly discussing the future of a loved-one relative who exhibited no conscious, cognitive, sentient responses, bringing forward relevant considerations for and against the continuation of life. This consultation took place after physicians expressed the opinion that there was no reasonable likelihood of Marcia Gray's returning to a conscious state and that there was no chance of her recovery. So here we have a situation where 1) the patient's chances of recovery to a conscious state are "close to zero" (at 583); 2) the patient expressed her desire several

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Medicine, No. 1 (Summer 1987), 53-63, and *Bruce Jennings,* "Last Rights: Dying and the Limits of Self-Sovereignty", 2 In Depth, No. 3 (Fall 1992), 103-118.

[29] *Gray by Gray v. Romeo* 697 F.Supp. 580 (D.R.I. 1988).

[30] The court also addressed the question of whether nutrition and hydration supplied through a gastrostomy tube are a form of medical treatment that the ward may properly refuse. This issue, however, is beyond the scope of this essay and deserves separate analysis.

times in the past not to be maintained upon reaching such a state; and 3) her family, which seems to be closely knit, with a history of mutual love, concern and support, exhibits a unified position that her dignity will be better served by letting her die. The court was right in honouring the family's request.

One final thought on the role of the family is relevant. It insists on the idea of the patient's close-ones consilium. The immediate family and the patient's most beloved-ones should make the treatment decision, with all competent close members whose lives will be affected participating. In this regard the only case ever to appear until now before the Israeli Supreme Court comes to mind.[31] The case involved a two-year-old baby, Yael Scheffer, who suffered from an incurable genetic disease commonly known as Tay-Sachs. Tay-Sachs causes neurological disorders and degeneration. Yael's mother appealed to the court, asking to terminate treatment other than that designated to relieve her suffering. Specifically, the appeal asked not to connect Yael to a respirator and not to provide her drugs through transfusion.

Deputy President Menachem Elon, who delivered the judgment (Justices Jacob Meltz and H. Ariel concurred), rejected the appeal. Quoting the attending physician's testimonial, Justice Elon argued that Yael Scheffer did not suffer any pain. She was treated in a way that did not infringe upon her dignity. Yael was kept clean, did not suffer from pressure bruises, and on the whole she did not cry. Yael cried, like any other child, when she wanted to be fed or when she suffered, like any other child, from stomach-ache, constipation, ear-infection, and the like. Yael resembled a bright candle. Under these conditions, the sanctity of Yael's life should have been kept, and this was the only value that determined the Court's decision. Any interference that offended Yael's life was contradictory to the values of Israel as a Jewish democratic state (para 64).

Justice Elon ended his very detailed ruling (150 pages long) by addressing the role of the family. The plea to refrain from treating Yael Scheffer was made only by the mother. The father did not join the petition, nor did he appear before the court. The mother explained this by saying that "he hates publicity". Justice Elon noted the fact that the father was the person who treated Yael each and every day, while the mother rarely visited her daughter in the hospital. The mother explained this by saying that she devoted her time to taking care of their other daughter, who was in a crisis. Justice Elon was not convinced that the father fully supported his wife's initiative. He said that in such matters concerning life and death, clear and explicit consent of both parents to the granting of such a petition is required (para 65). I concur in thinking that this consideration is crucial in estimating the role of the family. This is true for all cases and it is of crucial importance when the decision concerns the life of minors.

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[31] Civil Appeal 506/1988. *Yael Scheffer, through Talila Scheffer v. The State of Israel* (reasoning published in December 1993).

V. Conclusions

Let me sum up the considerations that we have to bear in mind in coming to decide on death with dignity. If the patient makes advance directives in the form of a living will, DNR order, a letter, etc. that he or she would wish to continue living, no matter what, then we should respect his or her wish.[32] The right to self-determination means that we should respect the patient's choice regardless of what he or she has chosen. To do otherwise would be to declare that this right of self-determination is reserved only to cases where patients wish to cease or to withhold treatment. If the patient leaves advance directives that he or she would rather die upon reaching a certain situation, but upon reaching that situation the patient shows every sign that he or she wants to continue living, then we have to respect present autonomy, however marred the patient's autonomy might be. If we are uncertain about the patient's present wishes because, for instance, he or she is in PCU with limited communication capacities, and the attending physicians think that the situation is irreversible, then we should respect the advance directives and let the patient die. For persons who prepared advance directives 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. The patients *themselves* may feel that their lives become transient and that the thought of death brings them more comfort than it alarms them. They feel that their dignity, their autonomy, their humanity is better served by letting them die. The patient's wish has to be respected. This is especially true if the patient has emphasized beforehand that his or her dignity cannot be separated from consideration of his or her beloved people. For some patients, the bare knowledge of the anguish their condition imposes on their families constitutes such a heavy burden on their conscience that they decide they would rather die and not be remembered in their weakness and impotence.

If no advance directives are available, we should ask the advice of the patient's beloved people, who supposedly know the patient better than anyone else. If the patient's beloved people believe that a point exists in keeping the patient alive, then we should respect their decision. This is true even if the attending physicians seem to think that no point exists in keeping the patient alive. In the event that the patient's beloved people wish to withhold treatment and the attending physicians think that a hope still exists that the patient may recover, then we have to respect the physicians' decision. It is better, from the point of view of the patient's best interests, to err on the side of life.

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[32] I am well aware that some people will contest this assertion because of the costs involved in maintaining patients (especially PCU patients) alive. It is beyond the scope of this paper to discuss economic considerations. I intend to dedicate a separate essay to this complicated question. Here I only say that it is within the responsibility of the liberal state to care for its citizens and not desert them at the point when they need its support more than ever. A bond exists between the state and its citizens which does not expire on the verge of death.

In the event that the patient's beloved people and the attending physicians believe that the patient's condition will only deteriorate and that that condition negates his or her dignity, the best interests of the patient may require allowing the patient die. I repeat, the best interests of the patient. Not the best interests of the family or his or her other close-ones, or the best interests of the physician (making room for another patient who has a better chance to enjoy life) or the hospital or the society at large.

Zusammenfassung

Gegenstand des Beitrags ist es, das schwierige Problem des Rechts, in Würde zu sterben, im Hinblick auf die Rolle der Personen zu überdenken, die dem Patienten nahestehen. Der Autor setzt sich zunächst kritisch mit einigen von Ronald Dworkin vorgetragenen Argumenten auseinander. Dann stellt er die relevanten Fallgestaltungen dar und untersucht drei Entscheidungen amerikanischer Gerichte: die Fälle *Saikewicz*, *Spring* und *Gray*. Der erste Fall, *Saikewicz*, betrifft einen Patienten ohne Familie oder andere ihm nahestehende Personen. Dieser Umstand hatte einen wesentlichen Einfluß auf die Entscheidung des Gerichts, von der Anordnung einer Behandlung des Patienten abzusehen. Im zweiten Fall, *Spring*, wünschte die Familie, daß der Patient nicht behandelt würde. Der Autor mahnt für alle die Fälle zur Vorsicht, bei denen die Umstände so beschaffen sind, daß das wohlverstandene Interesse der Angehörigen und das des Patienten kollidieren. Der Fall *Spring* ist ein Beispiel für eine solche Kollisionssituation. Der dritte Fall, *Gray*, dient als ein Beispiel, in dem sich das wohlverstandene Interesse des Patienten und das der ihm nahestehenden Personen decken. Zuletzt geht es um die Frage, ob die Angehörigen und andere dem Patienten nahestehende Personen in ihren Vorstellungen über das weitere Schicksal des Patienten übereinstimmen oder nicht. Die Frage verdient eine besondere Aufmerksamkeit.