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The Role of the Patient's Family, Surrogate and Guardian at the End of Life

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Abstract

The aim of this paper is to explore the intricate issue of the right to die in dignity by focusing on the role of the patient's family. The paper considers a number of real-life cases. The cases demonstrate the importance of caution in incidents when the best interests of the patient's family members contradict the best interests of the patient. There is some resemblance between two American cases: *Spring* and *Wendland*. But while in *Spring* the family was unified in its opinion to stop the patient's treatment, in *Wendland* family members expressed contrasting opinions. Two English cases - *In Re N* and *In Re 62-year-old Woman* and a Dutch case concerning Mrs A, highlight the important role of the incompetent patient's family when members of family are unified in their opinions. These cases lead to conclude, contra Dworkin, that advance directives should be treated with great caution.

Keywords

Advance directive, autonomy, care, clinical judgement, compassion, dignity, end-of-life, euthanasia, guardian, intellectual competence, patient's best interests, patient's family, person-centered healthcare, shared decision-making

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Accepted for publication: 19 June 2019

Introduction

The aim of this paper is to explore the intricate issue of the right to die with dignity by focusing on the role of the patient's family. The paper considers a number of real-life cases. These are, by no means, exhaustive cases, but they are illustrative, exemplifying common problems that occur in medical settings in the Western world. The cases demonstrate the importance of caution in incidents when the best interests of the patient's family members contradict the best interests of the patient. The two cases from Britain and The Netherlands will bring us to consider the role of advance directives at the end of life.

The question of how we can (or should) protect a person's autonomy is of major importance. People who believe that rational patients should have the right to arrange their own deaths, with the help of willing physicians, often appeal to autonomy as justification. But those who object to this idea claim that people who really want to stay alive might be killed, maintaining that leaving the decision in the hands of the patient's family might negate the patient's autonomy. Here, we have to distinguish between an implicit and an explicit desire to die and between formal and speculative autonomy. By *formal* autonomy it is referred to when the patient actually made a

decision. *Speculative* autonomy is what the patient would have decided if he or she had the ability to make a decision. In assessing speculative autonomy, much attention is given to the opinion of those representing the patient's best interests.

In *re Fiori*,¹ the mother of a Post-Coma Unawareness (PCU)² patient who lost consciousness in 1976, filed a petition requesting an order directing the nursing home to terminate treatment. The Supreme Court of Pennsylvania held that a close relative acting as substitute decision-maker, with the consent of two physicians, could remove life-sustaining treatment from the adult PCU patient where the patient left no advance directives. It could be assumed that, after so many years in this condition, the chances for a degree of recovery on the part of the patient were extremely slim. The Court emphasized that close family members are usually the most knowledgeable about the patient's preferences, goals and values and that they have "an understanding about the nuances of our personality

¹ *In re Daniel Fiori*, 543 Pa. 592, 673 A.2d 905 (2 April 1996).

² I explain why I prefer the term PCU to PVS in my book *The Right to Die with Dignity: An Argument in Ethics, Medicine, and Law* (Piscataway, NJ.: Rutgers University Press, 2001). I perceive the term PVS to be ethically problematic, arguing that the term "vegetative" undermines the patient's best interests.

that set us apart as individuals.”³

The conclusions of the American President’s Commission for the Study of Ethical Problems and Biomedical and Behavioral Research are relevant to the discussion. The President’s Commission argued that “the family is generally most concerned about the good of the patient” 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” [1].

Thus, family members, or other guardians, are permitted to make decisions on behalf of a patient on the basis of their acquaintance with the patient, believing that they know what the patient would have chosen were he/she competent to make decisions. The substituted judgement test is intended to determine with as much accuracy as possible the wants and needs of the individual involved. The reasoning is similar to that of John Rawls. Rawls suggests in *A Theory of Justice* that “We must choose for others as we have reason to believe they would choose for themselves if they were at the age of reason and deciding rationally” [2]. Rawls maintains that trustees, guardians and benefactors usually know the situation and interests of their wards and, thus, they can often make accurate estimates as to what would have been wanted [2].

Accordingly, when applying the substituted judgement test to determine whether an incompetent adult would refuse life-saving or life-prolonging treatment if he or she were competent, the decision of the patient’s family and his/her friends, particularly where that decision is in accord with the recommendation of the attending physician, is of particular importance. American law recognizes as valid a consent to treatment of an incompetent patient given in a traditional manner by the family, next of kin, or a guardian for treatment of an incompetent person.⁴ Note that the substituted judgement test assumes that people are able to reliably conclude what are the wishes of Aunt Jane, wishes that the average reasonable person might not have uttered because that person is not in the position of Aunt Jane.

³ See also *In re Daniel Fiori*, 438 Pa.Super. 610, 652 A.2d 1350 (17 January 1995). See also *In re Guardianship of Crum*, No. 404369, 61 Ohio Misc.2d 596, 580 N.E.2d 876 (19 September 1991). Conversely, in *W v M and others* [2011] EWHC 2443 (Fam) in Great Britain, application to the Court of Protection to authorise the withdrawal of artificial nutrition and hydration from a patient in a minimally conscious state on the basis of that patient’s previously expressed wishes and feelings was refused. Mr Justice Baker held that a best interests’ decision had to be made, that the patient’s life was not overly burdensome, that while she did experience pain and discomfort, and her disability severely restricted what she could do, the patient did have some positive experiences and there was a reasonable prospect that those experiences can be extended by a planned programme of increased stimulation. The preservation of life was a fundamental principle and the views of the patient’s family about her likely wishes were not to be given significant weight.

⁴ See *In re Guardianship of McInnis*, No. 145869, 61 Ohio Misc.2d 790, 584 N.E.2d 1389 (1 November 1991); *John F. Kennedy Memorial Hospital Inc. v. Bludworth*, 452 So 2d 921, (Fla 1984), p. 926; *In re Jobes*, 108 NJ 394, 529 A 2d 434, (NJ 1987), pp. 444-447; *In re L.H.R.*, 321 SE 2d 716, (Ga 1984), p. 723.

If treatment can be terminated when a PCU patient left no advance directive, upon reliance on the statements of the patient’s family, obviously it could be terminated when the patient had left such directives.

The patient’s best interests are at the centre of the analysis of the current paper. This term is beneficence-based. It calls for a clinical judgment about treatment options that would produce a clinically acceptable outcome for the patient. Such a basis excludes decisions that are maleficent. The paper’s methodology is based on extensive fieldwork in dozens of hospitals and research centres, on broad literature review, and on in-depth analysis of legal precedents. The paper critically analyses selected court cases from the United States, Great Britain and The Netherlands. It assesses the role of advance directives and of surrogates and guardians in protecting the patient’s best interests.

Cases

The following cases illustrate different cultures and approaches to treatment at the end-of-life, the importance of family in decision-making processes and the significance that is assigned in different countries to advance directives. Of the three selected countries, only The Netherlands currently practises euthanasia.

Spring

Earl Spring was an incompetent patient whose wife Blanche Spring petitioned the Court for an order that hemodialysis treatments, which were sustaining the life of Mr Spring, be terminated. Blanche and Earl Spring were married for more than fifty-five years. Their son Robert had lived nearby his parents’ home and had visited them virtually every day. Mrs. Spring and Robert Spring had been active participants in caring for Mr. Spring’s needs since the onset of his precipitous physical and mental deterioration. The burden that Mr. Spring had imposed upon his family after he developed renal failure was cumbersome. Blanche and Robert Spring had to transport Mr. Spring three times a week to a private nephrology center in another town for five hours of dialysis treatment [3]. Furthermore, Mr. Spring’s physical deterioration was accompanied by mental disorientation. His behavior at home became somewhat belligerent and destructive and he could no longer care for himself. 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 behavior and condition. After some six months, Mrs. Spring became well enough to be discharged from the hospital to her home. However, she could no longer take care of her husband and needed to devote all of her energies to taking care of herself [3].

At that time Mr. Spring was in a nursing home. His disruptive behavior was controlled through heavy sedation. Mrs. Spring and Robert Spring said that if Mr. Spring was 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. Nevertheless, the patient's family view was accepted by the Court.

Wendland

Advance Directives should be as clear and precise as possible. Speculation should be avoided, given that it might prove detrimental to the patient's best interest. Here, *Wendland v. Wendland* is a case in point [4].

In 1993, Robert Wendland was involved in a car accident while driving under the influence of alcohol. The accident left him brain damaged, immobile, and dependent on artificial nutrition and hydration. At the same time, he was minimally conscious. While Mr. Wendland was undergoing therapy, his wife Rose Wendland authorized surgery three times to replace dislodged feeding tubes. When physicians sought her permission a fourth time, she declined. She discussed the decision with her daughters and with Mr. Wendland's brother Michael Wendland, all of whom believed that the patient would not have approved the procedure even if necessary to sustain his life. Rose Wendland also discussed the decision with Mr. Wendland's treating physician, Dr. Kass, with other physicians, and with the hospital's ombudsman, all of whom supported her decision [5]. Mr. Wendland's mother and sister issued a lawsuit to prevent the implementation of the decision.

Rose Wendland was her husband's *conservator*, meaning that she had authority to make medical decisions for him. However, after a lengthy legal battle, the Supreme Court of California held that Rose Wendland had failed to show clear and convincing evidence that Robert Wendland would, under the circumstances, want to die. The Court emphasized that the clear and convincing evidence test requires a finding of high probability, based on evidence, "so clear as to leave no substantial doubt" [and] "sufficiently strong to command the unhesitating assent of every reasonable mind" [4]. If there is no valid healthcare directive, there must be *clear and convincing evidence* of *both* wishes *and* the patient's best interest. The Supreme Court of California concluded that the superior court "correctly required the conservator to prove, by clear and convincing evidence, either that the conservatee wished to refuse life-sustaining treatment, or that to withhold such treatment would have been in his best interest; lacking such evidence, the superior court correctly denied the conservator's request for permission to withdraw artificial hydration and nutrition" [4]. Consequently, the Court sustained the injunction to keep Robert Wendland alive.

In *Re N* [6]

N, a 68-year-old woman, was diagnosed with multiple sclerosis in 1991. Since 2007 she was provided with nutrition, fluids and medication through a tube. In 2015, N's daughter (M) appealed to The Court of Protection to stop her mother's life-sustaining treatment, arguing that her mother, who was in a minimally conscious state, had no quality of life as Mrs N would have perceived it. M told

the court that continuing treatment at this stage would be against her mother's wishes. She said:

"My mum's immaculate appearance, the importance she placed on maintaining her dignity and how she lived her life to its fullest is what formed her belief system, it's what she lived for. All of that is gone now, and, very sadly, my mum has suffered profound humiliations and indignity for so many years. I cannot emphasise enough how much the indignity of her current existence is the greatest contradiction to how she thrived on life and, had she been able to express this, then without a doubt she would" [7].

The Court of Protection authorised the request. Mr Justice Hayden ruled that treatment could be stopped after hearing evidence from medical experts as well as the woman's family. The judge decided that withdrawing the life-sustaining treatment was in the woman's best interests given her current quality of life [6].

Justice Hayden highlighted the observations of Baroness Hale in *Aintree University Hospitals NHS Foundation Trust v James and others* [2013] which emphasised that, in considering the patient's best interests, decision-makers must look at his medical, social and psychological welfare, the nature of the medical treatment, what it involves, the prospects of success and the likely treatment outcomes; "they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be" [8].

Justice Hayden, who said that his initial assumption was that "an instinct for life beats strongly in all human beings" [6], became convinced after hearing N's family that "Mrs. N would have found her circumstances to be profoundly humiliating and that *she* would have been acutely alert to the distress caused to her family, which *she* would very much have wanted to avoid" [6]. Expert witnesses testified that Mrs. N had no opportunity to achieve any kind of rehabilitation or recovery however limited. Thus, Justice Hayden was "entirely satisfied" that there was no prospect of "her achieving a life that *she* would consider to be meaningful, worthwhile or dignified" [6]. He concluded that N's wishes, "so thoughtfully presented by her family", coupled with the intrusive nature of the treatment and its minimal potential to achieve any medical objective, rebut any presumption of continuing to promote life. Quite simply, Justice Hayden wrote, "I have come to the conclusion that it would be disrespectful to Mrs. N to preserve her further in a manner I think *she* would regard as grotesque" [6].

Justice Hayden relied heavily on N's family who expressed a consensus opinion that her life was not worth living. At the end, no one stood by N to protect her right to life. N was a lonely woman. It is disconcerting to read that N "suffered profound humiliations and indignity for so many years". Undoubtedly, the family statements left a very strong impression in the minds of the Official Solicitor and the judge; compelling enough for them to abandon the presumption for life in favour of death.

In Re 62-year-old Woman

In another case in the UK, a 62-year-old woman who was severely disabled with arthritis, arrived at the hospital emergency department after taking a drug overdose with suicidal intent [9]. The patient left a suicide note and her husband presented clinicians with an advance directive stating that she did not want life-sustaining treatment. However, the advance directive had been made five years earlier, after the patient's parents died in an intensive care unit. The suicide attempt appeared to be precipitated by a recent acute deterioration of her arthritis [9].

The patient's husband emphasised that although the family would ideally want her advance directive followed, they would support any actions and treatment taken by the healthcare team [9]. The husband and other relatives testified that the patient repeatedly told them that she did not want to be admitted to intensive care.

Although the advance directive was deemed valid and consistent with the patient's beliefs and values, the clinical team decided to ignore it and to provide the patient with care. The reasons for the decision were fivefold:

- A delay in treatment regardless of the ultimate decision would prejudice the outcome.
- The advance directive did not specifically address the present situation.
- There was uncertainty about the patient's state of mind at the time of her taking the overdose.
- Her condition was likely to respond to treatment.
- It was felt that the risk of adverse consequences resulting from treatment was small [9].

At the six-month follow-up after discharge, the patient was grateful that the staff had acted in her best interests, but maintained that in view of her poor future prospects, she would rather have had her wishes respected [10]. But her wishes were not unequivocal. The medical team opted to act cautiously and to err on the side of life. The family did not wish to insist on any decision and left the final judgment in the hands of the medical team whose reasoning was perfectly logical and in the spirit of British medicine to maintain life whenever possible. Medical culture is of critical importance, as the next case exemplifies.

Dutch Alzheimer patient

This case concerns an elderly patient (70-80-year-old) with Alzheimer's disease in The Netherlands. Mrs A observed her mother deteriorate from dementia and she said she did not want to go through that herself. She was fearful of developing dementia [11,12]. After she was diagnosed as a patient with dementia, she explicated her wish not to be placed in a nursing home and separated from her beloved husband. Instead, she said that she preferred euthanasia

[11,12]. Mrs A drafted advance directives in which she stated that she wished to have voluntary euthanasia when she is still mentally competent and no longer able to live at home with her husband [11,12]. This was four years prior to her death, shortly after receiving the dementia diagnosis, but when she was still competent [11].

Two and a half years later, Mrs A revised her advanced directives, saying: "I want to make use of the legal right to undergo euthanasia whenever I think the time is right for this" [11]. This revised phrasing is significantly different from her previous advance directive, where she wrote: "I want to make use of the legal right to undergo voluntary euthanasia when I am still at all mentally competent and am no longer able to live at home with my husband" [11]. It should be noted that Mrs A never expressed a wish for euthanasia to the family physician, even when she was explicitly given an opportunity to do so by her physician [11].

Mrs A's husband took care for her until the last six months of her life. Seven weeks prior to her death, Mrs A was admitted to a nursing home because the husband could no longer take care of her at home [11,12]. The geriatrician in charge then met Mrs A for the first time, but did not speak to her. Instead, she spoke extensively with Mrs A's husband. On that occasion, the husband asked the nursing home geriatrician to implement Mrs A's euthanasia request based on her written advance directive. The geriatrician decided to adopt a more cautious route, giving Mrs A one month to accommodate herself to the new environment and then make a decision [11,12].

During the seven-week period that Mrs A stayed in the nursing home, the geriatrician observed the patient frequently and spoke to her for a long time. While Mrs A regularly told the care providers that she wanted to die, she did not ask for euthanasia. The physician thought that Mrs A no longer understood the words "euthanasia" and "death" [11]. When she was asked several times whether she wanted to die, Mrs A replied: "But not just now, it's not so bad yet!" [11]. Mrs A also regularly said "I don't want to die" [11].

Mrs A was unhappy in the nursing home. She was lonely, fearful, angry and restless, at time also violent [11,13]. Mrs A missed her husband. She enjoyed his company when he visited her and became edgy and sad when he left the nursing home. The husband visited Mrs A in the nursing home for two hours every day [11]. The geriatrician thought that Mrs A suffered unbearably as she was fine only when her husband and others visited her and showed clear signs of distress when she was alone. Furthermore, the geriatrician thought that the situation was hopeless and that euthanasia was therefore appropriate [11].

Once the geriatrician made the decision that euthanasia for Mrs A was appropriate, she consulted two physicians. Upon examination, both concluded that Mrs A suffered hopelessly and intolerably and that the legal criteria for euthanasia were met [12]. The first consultant observed the patient, had a brief meeting with her and spoke with Mrs A's husband and with her former family physician. She concluded that Mrs A was mentally incompetent and no longer capable of clearly expressing her wishes [11].

Therefore, Mrs A's advance directives should be honoured. In her report, partly based on the conversation with Mrs A's husband, the consultant concluded that the due diligence requirement was met [11].

The second consultant observed the patient, spoke with her and with her husband, their adult child, as well as with the patient's former family doctor. He agreed with the first consultant that Mrs A was incompetent and could no longer express clear requests, including euthanasia request. He also thought that Mrs A's advance directives should be honoured [11]. The second consultant was less sure whether Mrs A suffered intolerably. When he visited her, she appeared cheerful and satisfied [11]. But when the consultant watched videos of Mrs A, especially the heartbreaking scenes when her husband left the nursing home after visitation, he reached the conclusion that the loss of control caused Mrs A intolerable suffering [11].

On the morning of the euthanasia, Mrs A was not aware that this was her last day. The geriatrician later explained that there was no point holding such a conversation as Mrs A was incompetent. Raising the issue would "only interfere with the process" [11]. She thought that Mrs A might object to euthanasia [11]. As the physician thought that there might be a struggle, she decided to reduce Mrs A's consciousness. The physician put a sedative in Mrs A's coffee without informing her [11]. After Mrs A was in a state of reduced consciousness, a paramedic inserted an infusion line and the geriatrician injected thiopental; at which point, Mrs A tried to get up. Strikingly, the patient's family helped to hold her back and the physician quickly administered the rest of the thiopental and subsequently also a dose of a neuromuscular blocker [11,14]. The physician did not stop when Mrs A resisted because she did not think that it was "appropriate to halt termination of life," as euthanasia had been discussed for a while and the physician did not want the patient to "get cold feet" [15].

The geriatrician reported to the euthanasia review committee that the patient was not competent and therefore her wishes at the time of euthanasia were irrelevant. Even if Mrs A were to say: "No, I do not wish to die", the geriatrician would still continue with the euthanasia [11]. Apparently, Mrs A's husband was afraid that the euthanasia would not take place. He reassured himself that this was what his wife wanted [11,12]. The geriatrician acted as she did with the support of the family. If Mrs A's husband would have objected to his wife's euthanasia, then it is plausible to assume that the geriatrician would not have performed euthanasia.

The case gained notoriety because the Regional Euthanasia Review Committee did not think that the due diligence requirement was met. They concluded that the physician who performed the euthanasia failed to follow the Dutch statutory guidelines for euthanasia. While the euthanasia review committee thought that the physician could have reasonably concluded that Mrs A was suffering hopelessly and unbearably, that there were no other reasonable options, and that the physician appropriately consulted two experts, the Committee also thought that the physician failed to exercise due care [11,12].

The Committee thought that the answer to the question of whether the patient wanted her written advance

directives to replace her oral request was doubtful. The review committee observed that the patient never uttered a verbal request for euthanasia [11]. Therefore, it would have been prudent to maintain the more restrictive reading of Mrs A's dementia clause in her directives. The euthanasia request must be voluntary and well-considered and this was not the case here [11].

Furthermore, the committee felt that the geriatrician crossed the line in administering Dormicum, the euthanasia drug, in a deceitful way, without the patient's consent and by not stopping the euthanasia process when the patient responded negatively [11,16]. By sedating Mrs A, the physician wished to neutralise any objection. The Committee argued that the physician should not have continued with the implementation during which the patient had to be restrained and that any duress and even the appearance of duress must be prevented at any cost [11,17].

Consequently, the doctor involved was formally reprimanded for performing the euthanasia without the patient's proper consent [18]. The Committee recommended that the case should go to Court to clarify whether the doctor acted properly [19]. The Committee felt there was a need for judicial clarity regarding the powers a doctor has when it comes to the euthanasia of patients suffering from severe dementia [20].

Discussion

This discussion is divided to three parts. In the first part I discuss the role of the family in the decision-making processes concerning the above patients, while the second part examines the role of Advance Directives (ADs) at the end of life. The third part discusses surrogacy and guardianship.

Role of Family

The first case, *Spring*, illustrates a tragic situation in which the patient's wellbeing comes into conflict with the family's wellbeing. This presents a conflict of interest that was resolved by discontinuing Mr Spring's treatment and shortening his life. It seems 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 Earl Spring, they preserved his dignity. The question remains whether Mr. Spring himself would have preferred to die.

It is 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 circumstances. 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, especially under such stressed circumstances and even if it is, its interests are not necessarily identical to the interests of the patient. The patient's best interests should always be first and foremost in our mind [21-24].

The above cases illustrate that continuous strain inflicted upon close family members might bring them to decide that treatment should discontinue. The strain might be multi-dimensional: physical, emotional, psychological and financial [25,26]. In the *Wendland* case, Robert Wendland had two close family members who questioned the decision-making process, insisting that death was not in the patient's best interests. It might have been in the best interests of his wife who found it difficult to cope. It is reasonable to assume that the family dispute brought about the decision to continue treatment. If the family were to exhibit a unified stand to cease treatment, then no one would have questioned the non-treatment decision and the patient's life would then be shortened.

In all cases but in *Re 62-year-old Woman*, the families had strong views about what should the medical staff do with regard to their relative. In *Re 62-year-old Woman* the family expressed an opinion but left the decision in the hands of the medical staff. They did not wish to take responsibility for the outcomes resulting from any course of action and thought that medical staff are better equipped to weigh the various options and to make a decision.

As for the Dutch patient: As in previous cases discussed *supra*, the patient's family found itself in an impossible situation. Mrs A could no longer be treated at home. Her exhausted husband was unable to provide the care she needed. Her situation required an alternative solution: a nursing home, the solution that Mrs A dreaded. The review committee wrote that Mrs A's husband was "a very gentle man" who found his wife's farewell frightening [11]. He was overwhelmed by her placement in a nursing home and felt guilty. However, the situation at home escalated to such an extent that he was at risk of collapsing [11]. The husband was mainly afraid that the euthanasia would not take place. After his wife was euthanised, he gave the family physician the impression that the termination of his wife's life occurred calmly [11]. He did not wish to share the drama.

Mrs A's story exemplifies the difficulty of entertaining euthanasia for incompetent patients [27]. Her family physician, who knew her for years, met with Mrs A and her husband a few months prior to her death. At that time, Mrs A could no longer understand the concept of euthanasia. When the physician explained what euthanasia means, Mrs A said that she did not want it. The husband then reminded her that she did not want to be admitted to a nursing home and Mrs A replied that in that case she might want euthanasia. The physician explained that she would receive an injection and would not wake up. Then Mrs A said that this "was going too far" [27]. Mrs A could not determine what was worse for her: a nursing home or euthanasia and she was no longer competent to make a decision. Her dementia had relinquished her autonomy and thus a decision had to be made for her. Her advance directives were open to the interpretations of family and

medical professionals. It is doubtful whether their interpretation to terminate Mrs A's life, especially in the way the euthanasia act had manifested itself, was in accordance with what Mrs A wished for.

Advance Directives

Advance Directives (ADs) are often made without the opportunities for fully informed consent. On what basis did the patient make the decision that she would not want to be treated? The decision not to receive treatment should be based on a clear understanding of the situation. It is essential that the patient understands the disorder, the available alternatives and her chances and risks. This can be rather complicated when the physicians themselves do not have a clear picture about the condition and cannot provide a reliable prognosis.

Furthermore, there are valid concerns about the patient's opportunity to change her mind, the potential for scientific developments and the clarity of the advance directive. In a patient who is mentally alert and who makes a decision not to receive treatment, there is always the opportunity for the clinician to consider with the patient the reason for the decision in light of the particular clinical features. The clinician also has the opportunity to discuss with the patient why she does not want treatment. Is it fear of pain, loss of dignity, concern for others or any other reason? In these circumstances, the clinician is in a better position to ensure that the patient has thought out the decision carefully. This possibility is removed when faced with an AD and an incompetent patient [28,29].

As for the potential for scientific progress, competent patients have the advantage of making their decision based on up-to-date knowledge. Advance directives may be made many years prior to the time of their implementation, a period during which new treatment or changes in quality of life opportunities may have occurred. In addition, ADs are not always clear about the patient's intentions. A leading British physician, Keith Andrews, testifies that he saw an AD stating that if the person developed severe brain damage she would not want to continue living. There was no statement as to whether this decision was to be made on the first day or after a period of several days/weeks/months to give the patient opportunity of recovery. The general statement about severe brain damage gives wide latitude for widely differing views, even among clinicians experienced in the management of brain damage [28].

In England and Wales, the Mental Capacity Act (MCA) (2005) enshrines the concept of autonomy. It holds that if a person has made an advance decision which is valid and applicable to a treatment, the decision has effect as if he had made it, and had capacity to make it, at the time when the question arises whether the treatment should be carried out or continued. Section 26 (2) of the Act maintains that a person does not incur liability for carrying out or continuing the treatment unless, at the time, he is satisfied that an advance decision exists which is valid and applicable to the treatment. Section 26 (3) provides that a person does not incur liability for the consequences of withholding or withdrawing a treatment from a patient if, at the time, he reasonably believes that an advance

decision exists which is valid and applicable to the treatment [30].

In *Aintree University Hospitals NHS Foundation Trust v James*, [8] Lady Hale, who delivered the opinion of the Court, wrote that a physician cannot be forced to provide treatment that is not clinically indicated for a patient and, conversely, a doctor cannot lawfully provide treatment that is not in the patient's best interests. The key question concerns as to how to determine what is in a patient's best interests. Lady Hale maintained:

“... in considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the places of the individual patient and ask what his attitude to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be” [8].

For the first time, the Court ruled that if it is in a mentally incapacitated person's best interests, it would be lawful for life-sustaining medical treatment to be withheld. Lady Hale stressed that, in accordance with the MCA, consultation with carers and others interested in the patient's welfare as to what would be in his best interests and in particular what his own views would have been is paramount [8].

In the Netherlands I have seen ADs saying: “I'd like to die upon the stage when I don't recognize my children” [31,32]. This phrasing is far too vague and too sweeping to serve as a guideline. It provides healthcare professionals with wide latitude for interpretation that might not always be in tandem with the patient's best interests. Medical conditions are varied and complex. ADs that are usually phrased in general terms might be ill-suited to serve as guidelines to follow. We also saw that in both in *Re 62-year-old Woman*, and in the case of the Dutch Alzheimer patient, the advance directives were open to interpretations and, in the case of Mrs A, it was unclear whether the patient was adequately competent when she revised them.

Mrs A's revised advance directives stated: “I want to make use of the legal right to undergo euthanasia whenever I think the time is right for this” [11]. It is reasonable to deduce that Mrs A thought that she herself would request euthanasia at the time of her choice. Therefore, it would have been prudent to adopt a more restrictive reading of the advance directive. The geriatrician should have prioritised Mrs A's statements that she was not ready to die over the earlier advance directives.

During the seven-week period that Mrs A stayed in the nursing home, the geriatrician observed the patient frequently and spoke to her for a long time. While Mrs A regularly told the care providers that she wanted to die, she did not ask for euthanasia. The physician thought that Mrs A no longer understood the words “euthanasia” and “death” [11]. When she was asked several times whether she wanted to die, Mrs A replied: “But not just now, it's

not so bad yet!” [11]. Mrs A also regularly said “I don't want to die” [11]. Still, the physician decided to honour the family's request rather than the patient's life.

In his book *Life's Dominion*, Ronald Dworkin made two pertinent distinctions. The first is between good life and biological life. A “good life” is a normative concept whereas biological life refers to bodily functions. Clearly, a life of biological existence alone does not encompass the full meaning of life. But it may still be a life worth living. Dworkin did not think so. Dworkin argued that there is no point in continuing to “live” when only a body remains, without autonomy and spirit [33].

The second distinction is between *experiential* and *critical* interests. By *experiential* interests Dworkin referred to pleasure and enjoyment in virtue of desires and ambitions. *Critical* interests refer to our wish to live worthwhile lives [33]. Dworkin emphasized the notion of dignity. Dignity is the central aspect of the intrinsic importance of human life [33-35]. A person's right to be treated with dignity involves the expectation 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. Now, Mrs A had a critical interest in having a family. This critical interest was connected to her convictions about the intrinsic value of her own life. Mrs A did not wish to be in a nursing home, dependent on others. Dworkin wrote that many people do not want to be remembered living in circumstances perceived 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 contended that some people are horrified that their death might express an idea which they detest as a perversion: that mere biological life - just hanging on - has independent value [33].

Dworkin contemplated 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 asked whether autonomy requires that her wishes be respected 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 sandwiches’. In such a case, an apparent contradiction seems to exist between past and present wishes, between past and present autonomy. Dworkin endorsed respecting Margo's past wishes, arguing that a competent person making an advance directive to provide for her treatment if she enters into dementia is making the kind of judgment that autonomy, in the integrity view, most respects a judgment about the overall shape of the kind of life she wants to have led [33]. In other words, Dworkin argued that a life that is lacking 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. Dworkin would probably think that the physician was justified to euthanise Mrs A. He showed little respect to life that lacks intellect [33].

Contrary to Dworkin's arguments, in *The Right to Die with Dignity* I contended that even the thin pleasure of peanut butter and jelly is worthwhile [32]. Evidence shows that many people who reach the stage of permanent

dementia and live non-autonomous lives nevertheless hang on to life and find pleasure in things that had no importance for them in the past [36-38]. Despite what we would expect, older adults with dementia do not focus on the disease when talking about their happiness. Some patients with dementia suffer from mood and personality changes, but their experience of happiness remains firmly grounded in their social relationships. Becoming engaged in activity improves how they feel about themselves, especially when activities are accompanied with music [39,40]. This explains why Mrs A said, when asked whether she wished to die: "But not just now, it's not so bad yet!" [11]. Some months before she thought that the nursing home would be horrible, but after she was admitted to the nursing home she thought that the situation was bearable.

Therefore, I argue that her present order of priorities should win over past considerations. Dworkin seemed 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 clearly doubtful. People do change and these changes may become meaningful to us in circumstances that we cannot envisage. Indeed, the very idea of autonomy reflects our ability and desire to construct and reshape realities, to re-evaluate values and ideas, to renounce old beliefs and to accommodate ourselves to new situations.

Dworkin assumed that people, as rational agents, may have certain attitudes regarding dementia and decide beforehand that some forms of life are repugnant, meaningless and not worth living. However, for many people, the life of intellect is not as important as it was for Dworkin. Indeed, many people are not self-assured of their future wishes as Dworkin was. People try to assess how their situation might look in the future and decide on their destiny according to the data they currently have on the demented state. Many people do not possess the same capacity of assessment that Dworkin was fortunate to have. Moreover, people are not only thinking creatures. Not all factors can be grasped by our rational faculties. Not all data can be assimilated by applying reason and judgment. Sometimes, we do things we could not imagine doing. Sometimes people act in accordance with their sentiments, rather than their intellect. As a consequence, people are pushed to do some things by their instincts and impulses, factors that they find difficult to explain in rational terms. On some occasions people are overpowered and overwhelmed by the reality that confronts them. Here, they accommodate themselves to situations that have been imposed on them.

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 and experience, but we cannot know with absolute certainty that these assessments will prove to be true for us. Following Dworkin, let us consider Mrs A who was able to

enjoy only a small number of things, first and foremost the company of her family. From her previous directives it was understood that if the time would come and she would need to live outside of her home then this sparse kind of pleasure was not worth living for. However, upon reaching that stage Mrs A hung on to life and nevertheless found some pleasure in her limited life. Her world was filled with joy upon seeing her loved ones. On the other hand, no concrete indication was given that she wanted to depart from life. In such a case, the patient's present condition should trump her previous advance directives.

In coming to decide the fate of incompetent patients, such as those who have entered into dementia, consideration should be given to whether the patient's condition is irreversible; whether a chance exists for rehabilitation of some constitutive, vital elements of human life; the feasibility of maintaining a reasonable quality of life that is of significance to the patient in concern; whether the patient expressed his or her desire to die upon reaching a certain state of living, and also whether we feel the patient's current interests are similar to the interests he or she expressed in the past. These preconditions affirm values that liberals, as well as conservatives, so much appreciate, for example, autonomy and respect for the dignity of the person. Other relevant considerations include the opinions of physicians and of the patient's family and/or guardian. The AD, together with family testimonials, can shed light as to whether the present quality of life is reasonable for the patients and of significance to them. The medical care team should consider the length of time that has passed since making the advance directive, changes in the patient's condition, the circumstances that the patient is now in and the likelihood of successful treatment.

Re 62-year-old Woman illustrates the need to refresh ADs so to ascertain patients' wishes; more so when the last draft of the AD was made under the influence of a traumatic event. In the case of Mrs A, most disturbing was the physician's statement that since Mrs A was no longer mentally competent, her utterances were irrelevant at that time in the physician's opinion. Even if Mrs A had said prior to the implementation that she did not want to die, the physician stated that she would have proceeded with the termination of life [11]. The physician took upon herself the responsibility to kill a patient, although the patient, if asked, would have opted for life, and she denied the patient the opportunity to bid her loved ones farewell against the clear wishes of the patient. This conduct should disturb first and foremost the Dutch medical establishment. They should reflect on the consequences that the euthanasia law has brought about, consequences that cannot be reconciled with the humane motivations for euthanasia that stress first and foremost the dignity of the person.

For sure, we should be wary of the impact that financial considerations may have in deciding the fate of the patient. In the US, there are fears that ADs will be utilized against the patient's best interests to preclude the commitment of costly resources. It has been argued that advance directives have not fulfilled their promise of facilitating decisions about end-of-life care for incompetent patients. Furthermore, many legal requirements and restrictions

concerning advance directives are counterproductive [41-44]. The advance directive must be applicable to the present circumstances.

To resolve the conflict between past competent and current incompetent interests, it is suggested that instead of simply enforcing all prior directives, doctors, families and other people involved in the care of incompetent patients, should be able to examine whether the patient's interests would best be served by actions contrary to the AD, in situations in which the incompetent patient appears to have an interest in further treatment and life [9,45-48].

Surrogacy/Guardianship

In situations such as that of Spring, where a clear conflict of interests arises and the patients' family is incapable of making a decision for the patient that is independent of the family members' own best interests, it is advisable to enquire whether the patient has a surrogate or to appoint a guardian for the patient. A *surrogate* is a person who has enjoyed the patient's trust. The patient had thought that the surrogate will be able to make decisions on his behalf when competency is lost due to the deteriorating disease. The surrogate is assumed to know the patient well and to be familiar with his value system and preferences and to be a voice for the voiceless patient. Though the patient is silent, he has a trusted surrogate who represents his best interests and makes decisions as if it is the patient himself who makes them. A *guardian* is an impartial agent who understands the complexity of the situation and who could truly represent the patient's best interests. Guardianship is when a Court appoints someone to have legal authority over the patient's care, custody and control. Surrogate decision makers require support in the form of active information and structured communication [49,50].

In Re N, the patient's interests were represented by the Office of the Official Solicitor, which acts for people without mental capacity to make decisions themselves [51]. The Official Solicitor first held that there should be strong presumption supporting the continuance of life, stressing that there was no direct evidence as to what N wanted for herself and that the right judgment should take into account not how N presented before her current suffering, but whether no life at all are preferable to her present condition. However, after hearing N's family observations, the Official Solicitor concluded that it would be wrong for him to continue to oppose the application [6]. The Official Solicitor indicated during the course of the hearing that he supported the application to withdraw life-sustaining treatment, meaning that the application to cease treatment was not opposed by any of the parties involved [6].

This was the first time that the Court of Protection has agreed to withdraw treatment from someone receiving life-sustaining treatment while considered by medical experts to be in a 'minimally conscious state'. In 2011, the Court of Protection ruled that treatment could *not* be withdrawn from a patient in a minimally conscious state, at the family's request [52].

When a patient like Mrs A is declared incompetent and decisions regarding her treatment are required, the medical team should have appointed a patient's guardian to make a

decision. Mrs A's husband was incapable of ensuring his wife's best interests, as these were conflicting with his own best interests. While he felt guilty for relocating his wife to a nursing home, he nevertheless understood that this was necessary. He visited his wife each and every day, but only for two hours. This was the right balance for himself. Clearly, this was not the right balance for his wife. As his wife's medical condition could not have been improved, in fact quite the opposite, the situation became increasingly agonizing for him. He came to the realization that death was the appropriate solution for him and for his wife. It was wrong not to appoint a guardian in such a situation. A guardian could possibly have explored other solutions that would have served the patient's best interests better.

Things are relatively less complicated when the patient had made an AD that provides clear guidelines for the medical team about the course of treatment to pursue, including no treatment and where a surrogate or guardian is in agreement with the AD. In the absence of a clear indication of the patient's wishes, the medical team may consult the surrogate or guardian, asking her what the patient's choice would have been likely to be if she was able to utter a preference. If the surrogate who knows the patient or the guardian, recently appointed to represent the patient, does not have sufficient knowledge about the patient to deduce her preferences, she/he is supposed to make a recommendation on the basis of her/his beliefs about where the patient's best interests lie [53].

Sometimes, the surrogate or guardian might make a decision that is incompatible with the patient's advance directive. The AD might be too general and the surrogate would claim that it does not encompass the specific situation in which the patient has found herself. Based on intimate acquaintance, the surrogate may claim insights that are unspecified in the AD. Then the decision as to whether to follow the patient's AD or the patient's surrogate opinion is left in the hands of the medical team. The nagging concern is whether the medical team will decide the case solely on the basis of what is best for the patient, rather than what is best for the hospital. This concern is justified and, presently, there is no generally accepted yardstick that would instruct and direct the decision-making process. Clinging on to the notion of the "patient's best interests" might be insufficient, as these are not always clear-cut. People have conflicted opinions and might exhibit indecision when they are competent, yet the situation becomes far more compounded when they become incompetent patients.

Suppose that the patient had voiced conflicting views on the use of sedation. The surrogate heard the patient voicing those conflicting views. The AD is silent about sedation. If the surrogate shares all that she heard from the patient, no problem arises. The problem arises when the surrogate shares only part of what she heard either intentionally or because at present she remembers only that part. It is also possible that the surrogate would remember some things because unconsciously she does not wish to remember certain things. Either way, the surrogate then does not fully represent the patient. As the surrogate's intentions might not be explicit and apparent, the medical team is incapable gauging the extent of patient's representation assumed by the surrogate.

Conclusions

In the United States, oral statements are perceived sufficient to remove or to withhold life-sustaining treatment [54-59]. The family may play a crucial role in deciding the destiny of their loved ones. In *re Christopher* [60], the court relied on a conversation that was held ten years before the case between 79-year old Ms. Kushnir and her son to accept the son's *bona fide* refusal to consent to any procedure that will prolong the patient's life after she lost all cognitive functions and was in constant pain. The surgical insertion of a feeding tube was conceived by the Court under these conditions as "futile and unnecessary" [60,61]. Because of the weight that is accorded to the opinion of the patient's family, one of the medical staff, arguably the social worker, should review the relationships between the patient and his/her family to verify that the family does not hold partisan interests that run counter to the patient's best interests. After all, the family does not necessarily represent the patient's best interests as a matter of course. We should always try to ascertain that those who are truly beloved, truly caring for the patient and those who are around the patient's bedside, be included within the decision-making process together with the medical staff themselves.

Summing up the considerations that are important in decisions on death with dignity, my view is the following: if the patients are competent, their requests should be honoured and respected as much as it is possible. The situation is far more complicated when patients are incompetent. If patients make advance directives in the form of a living will, DNR order, a letter, *etc.*, that they would wish to continue living, no matter what, and we have no reason to believe that the patients have changed their minds, then we should continue to respect that wish.

In the event that patients have prepared an AD saying that they would prefer that all treatment be terminated upon reaching the last stage of their incurable disease, and we are uncertain about the patients' present wishes because, for instance, they are incompetent, and the attending physicians think that the situation is irreversible, then we should respect the AD and let the patients die. When the healthcare professionals are satisfied that the advance directive is valid and applicable to the patient's condition in the current circumstances, then it should be followed [47,53].

For people with foresight who took the initiative to prepare ADs, asking to die upon reaching a certain situation, death is *not* the worst situation one can be in when compared to being on the verge of death and then stabilized without hope of ever really getting better. Patients who suffer from incurable diseases (such as cancer) may feel that their lives become transient and that the thought of death brings them more comfort than alarm. They may feel that their dignity, their autonomy, their humanity, are better served by letting them die. The patient's wish, in this context, must be respected. This is especially true if the patient has emphasized beforehand that her dignity cannot be separated from consideration of her loved people. For some patients, knowledge of the

anguish their condition imposes on their families is such a heavy burden that they prefer to die and not be remembered in their diminished condition. This, of course, is not the sole consideration, but a significant additional consideration that needs to be taken fully into account.

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

In the event that the patients' family wishes to and the attending physicians believe the patients' condition will only deteriorate, and that that condition negates their dignity, the best interests of the patients require allowing the patients to die. Here, the best interests of the *patients*, not those of the family, the physician, the hospital, or the Society at large, are and remain, paramount.

Acknowledgments and Conflicts of Interest

I am grateful to Deputy President (ret.) of the Israel Supreme Court, Justice Eliyahu Mazza, Dan Callahan, Shimon Glick and Scott Kim for their most constructive remarks. I declare no conflicts of interest.

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