Refusing and withdrawing treatment at the end of life: ethical complexities involving patients who lack decision-making capacity

Rechazar y retirar el tratamiento al final de la vida: complejidades éticas que involucran a pacientes que carecen de capacidad para tomar decisiones

Marie-Jo Thiel*

https://doi.org/10.36105/mye.2020v31n4.07

Abstract

Obtaining valid, free and informed consent is not always very easy. It presupposes on the one hand disclosure of fair, clear and appropriate information, and on the other hand the capacity to understand as properly as possible, and then to take a decision. So when a patient has long-term cognitive impairments and lacks the capacity independently to make or communicate a decision and when this decision is about his or her end of life, the consent may be very complex. how to do it right?

The present article does not give «the» solution but it discusses the issue in the French legal and ethical framework. The challenge is to find a crest line between beneficence, respect for autonomy and the refusal of «unreasonable obstinacy» (which defines futility in French Law). Beneficence might mean withdrawing (or

* University of Strasbourg, France. Email: mthiel@unistra.fr https://orcid.org/0002-9987-3383

Reception: June 20, 2020. Acceptance: July 15, 2020.

with holding) ongoing medical treatments (chemotherapy, radiotherapy, etc.) when they become increasingly ineffective and furthermore, are aggressive and intrusive for the patient (leading to a decrease in his quality of life). But when the patient cannot consent or seems to disagree, how can we go forward?

The contribution will first examine the value of patient decision making and consent in health care and then the role that family and caregivers can play in supporting these. Since death is a unique, definitive moment, we must not forget that often the experience of relatives with the patient conditions both the decision-making process and their mourning process. Finally, I will examine and discuss three specific clinical situations when a decision has to be made regarding withholding and withdrawing of treatments: when a patient is conscious, when he/she is unconscious and has no advance directives, when he/she knowingly refuses treatment. The struggle is to know what truly matters to the dying person in order to respect his or her wishes.

Key words: consent, advance directives, trustees, family-centered care, medical information.

Quite often at the end of life, families are faced with the ethical question, not of stopping care that is always due (1), but of stopping ongoing medical treatments, especially those that are aggressive and intrusive for the patient. Such treatments –chemotherapy, radiotherapy, surgery, etcetera– might result in a decrease in quality of life for the patient while becoming increasingly ineffective. French law (framework of this paper) describes this situation of futility with the expression «unreasonable obstinacy».

Withdrawing treatments in this context can be ethically controversial when the patient has long-term cognitive impairments and lacks the capacity independently to make or communicate a decision at (and about) the end of his or her life. If the patient has given clear advance directives or appointed a trusted person to support or represent them, decisions regarding these treatments

might be easier. Sometimes, however, there are no advance directives. Family members might be torn apart over interpreting the undeclared wishes of their loved one. The Vincent Lambert case in France (2) is emblematic of this situation. In other cases, however, the patient's family is not even present at all. How, then, do we resolve ethical problems regarding withdrawing treatment?

End-of-life situations compound the difficulties of obtaining valid, free and informed consent in the case of persons with cognitive impairments. Even without such impairments, it is not clear how to avoid all the pitfalls of substituted consent and its misrepresentations, particularly in the Anglo-Saxon world where studies involving patients who have decision-making capacity and their family members point «in a third of cases to a mismatch between the patient's wishes and those of his or her family». (3) This highlights the importance of trying to know what truly matters to the dying person and to respect his or her wishes, values, feelings, and beliefs regarding end-of-life healthcare decisions.

In this paper, we will first examine the value of patient decision making and consent in health care and then the role that family and caregivers can play in supporting these. I will propose that death is a unique, definitive moment, and often the experience of relatives with the patient conditions both the decision-making process and their mourning process. Finally, I will examine and discuss three specific clinical situations when a decision has to be made regarding withholding and withdrawing of treatments.

1. Consent in medicine

The value of consent in medicine is not longstanding. For a long time, the supposed beneficence of paternalism prevailed. In the 1947 French Code of Medical Ethics, article 30 stated: «the doctor must endeavour to impose the execution of his decision». The evolution of social attitudes as well as medical technologies intro-

duced a patient's informed consent as a necessary (but not sufficient) condition to guarantee the validity of the medical act and the expression of the patient's autonomous decision. French positive law is evolving: The laws of abortion in 1975, organ removal in 1976, medical experimentation in 1988 and bioethical laws in 1994 are all opportunities to establish the importance of consent in medicine. The Kouchner law of 4 March 2002 provides that:

> No medical procedure or treatment can be performed without the free and informed consent of the person, and this consent may be withdrawn at any time (article L. 1111-4 of the Public Health Code).

It echoes the 1995 Code of Medical Ethics which also incorporates in article 36 that «the consent of the person examined or cared for must be sought in all cases». This obligation, however, presupposes disclosure of «fair, clear and appropriate» information (Article R4127-35 of the French Public Health Code) regarding the patient's clinical situation, the usefulness of the treatment, its consequences, its benefits and risks, «other possible solutions and the foreseeable consequences in the event of refusal,» (Article L. 1111-2 of the French Public Health Code) particularly in palliative and ambulatory care. «[T]he prognosis of a terminal condition must be revealed only with caution, but relatives must be informed, except in special circumstances or if the patient has previously prohibited this disclosure or designated the third parties to whom it must be made». (Article R4127-35 of the French Public Health Code). It should also be noted that there is no right to dispose of one's body in French legislation (4). While this legal framework is essential, it raises many ethical questions because of both the profound vulnerability experienced by patients at the end of life and psychiatric issues that might compromise decision-making capacity in patients. Nonetheless, as long as we are not dead, we are alive, as Paul Ricoeur recalls in his posthumous book *Vivants jusqu'à la mort* 2007 (5). A certain form of communication

in patients, even in those with cognitive impairments, near the end of life always remains.

Consent is an «I want», writes Paul Ricoeur 1950 (6). It is an essential manifestation of human freedom and the outcome of a decision-making process that is both rational and emotional, voluntary and involuntary. Etymology reminds us that *to consent* comes from the Latin *consentire* which is usually translated as «to agree with». A more literal and more accurate translation, however, is «to feel with». To consent is to «intuitively grasp, in a sensitive way», not only the stakes of a clinical situation *with* myself (i.e., my opinions and my beliefs) but also *with* others in order to accept a proposal for medical treatment that is not disruptive to my existence-with the doctor who informs, family members and other caregivers, because they too are part of my existence. In patients with dementia and other cognitive impairments, we should never forget the emotional dimension of decision making and consent. The way in which we speak with patients with dementia, such as holding a hand, smiling, positioning face-to-face, using the patient's mother tongue, and plain language, could all contribute to a closeness with the patient from which others sometimes can interpret the will of the patient and elicit implicit or explicit consent.

Consent is only valid, however, as long as it is not revoked. For a person with cognitive impairments, emotions remain a means of communication that can call into question whether this person has provided valid consent, as in the following case involving an 80-year-old Dutch woman with dementia. She had earlier expressed a desire for euthanasia when she deemed that 'the time was right', but...

> As her situation deteriorated, it became difficult for her husband to care for her, and she was placed in a nursing home.
>
> Medical paperwork showed that she often exhibited signs of fear and anger and would wander around the building at nights. The nursing home senior doctor was of the opinion that she was suffering intolerably, but that she was no longer in a position where she could confirm that the time was now right for the euthanasia to go ahead.

> However, the doctor was of the opinion that the woman's circumstances made it clear that the time was now right.
>
> The doctor secretly placed a soporific in her coffee to calm her and then started to give her a lethal injection.
>
> Yet while being injected, the woman woke up and fought the doctor. The paperwork showed that the only way the doctor could complete the injection was by getting family members to help restrain the patient.
>
> It was also revealed that the patient said several times, 'I don't want to die', in the days before she was put to death, and that the doctor had not spoken to her about what was planned because she did not want to cause unnecessary extra distress. She also did not tell her about what was in her coffee as it was likely to cause further disruptions to the planned euthanasia process (7).

We must say that, in this case, the woman with dementia revoked her advance directives and did not, in her present circumstances, consent to euthanasia. The information that is required to ensure informed consent is never neutral, but in this case, it was not even given.

Information about the end of life is crucial to disclose in seeking consent from patients regarding their health care. As I have written elsewhere, health information (diagnosis, prognosis...) is «a word that in-forms, that enters within the being where it forms and deforms it, letting the «*have*» become an usurper which changes the identity of the *being* in such a way that *having* a disease becomes *being* sick» (8). The psychiatrist Jean-Jacques Kress notes that, «[I]nformation does not simply consist in transmitting data because what is considered by the practitioner as a category of knowledge becomes truth for the patient's unique existence... By knowing the prognosis, the person is affected in his or her relationship to his or her destiny, to the form that the rest of his or her life may take» (9).

Sometimes, it might be difficult for patients to hear disclosure of a life-limiting condition. Total or partial denial is not rare, especially when there is already some degree of cognitive impairment experienced by patients. In all cases, this knowledge produces

«subjective effects» that confuse the patient, even though it is intended to be «knowledge about the patient's *well-being*», while the doctor often consciously or unconsciously expects a «submission, as if it were self-evident.» (10)

The ideas of good, benefit, or beneficence inherently relate to consent: proposing mistreatment would be unethical. What should be done, however, if a patient makes an unacceptable or irresponsible decision, for example, when the patient refuses essential and reasonable care that, should the doctor not give it, would be medically negligent?

When such a patient is assessed to lack decision-making capacity, acting in the best interest of that patient is a useful principle, but this should not dissimulate the fact that it is sometimes very difficult to establish what is good for another person. The good to be done might not be perceived similarly by the doctor and the patient since their relationship is asymmetrical, the latter being at the end of life, in a situation of extreme vulnerability, often not able to understand relevant information or capable of appreciating and judging benefits and burdens. The tension between respecting a patient's autonomy and beneficence towards this patient is heightened when the patient is unconscious and/or lacks decision-making capacity and has no advance directives. In these circumstances, it is the health professional's or caregiver's beneficial action that must take precedence, writes Manuel Wolf, although this must be «accompanied by solid safeguards based not only on the law, but also on the education and empowerment of each actor in the care relationship, whether this be the healthcare professional or a simple citizen» (3). Expanding the hermeneutical circle regarding what is beneficial for the patient to include the patient's family members and other caregivers is a paradigm shift in clinical and ethical decision making. It incorporates complex thinking. It prohibits the handing over of decisions solely to the doctor but requires also involvement of the family and other caregivers.

2. The role of family members and other caregivers in supporting patient consent

a) Family

The patient's consent to treatment protects against control by others of the decision-making process in health care, whether this be the doctor with his or her knowledge or relatives who are always at risk of being caught up in denial of a loved one's end of life or, conversely, in the certainty that everything is already over and that there is no longer any need to conserve the patient's life. At the same time, whether we like it or not, the presence of family members who are in a person's life affects the behaviour and decisions of the patient, especially in the case of persons with cognitive impairments, such as dementia. The patient's family is often influential in his or her decision to continue or stop treatments, and the role of family members is in turn affected by the manner in which they themselves experience this situation. If the patient returns home to die, other parameters influence the lived experience: the frequent idealization of the home but also the intrusion into the living spaces of the home, the fact that sometimes time has become too short while relatives are exhausted. This is why it is important to communicate well with families, especially if patients are unconscious, lack decision-making capacity, have not formulated advance directives or designated a trusted person to represent them or, in France, are not covered by a «future protection mandate» (https://www.service-public.fr/particuliers/vosdroits/F16670).

In France, unlike some Anglo-Saxon countries, there is no place for substituted consent in place of the patient (e.g., through guardianship). Article 8 of the Claeys-Leonetti Act of 2016 reinforced the weight of advance directives precisely in order not to put the weight of the decision on the family. Article L. 1111-11 of the Public Health Code now provides that:

> Advance directives are binding on the physician for any decision to investigate, intervene or treat, except in cases of life-threatening emergency for the time necessary for a full assessment of the situation and when the advance directives appear manifestly inappropriate or inconsistent with the medical situation.
>
> The decision to refuse to apply the advance directives, which the doctor considers manifestly inappropriate or not in accordance with the patient's medical situation, is taken at the end of a collegial procedure defined by regulation and is entered in the medical file. It is brought to the attention of the trustee designated by the patient or, failing that, of the family or close relations.

In France, the family does not therefore have to decide for the patient if instructions in advance directives are inadequate. It is only if the patient is unconscious and has not written advance directives that the doctor asks, not about the family's decision, but for their testimony regarding the patient's presumed wishes. Article 10 of the Act refers to Article L. 1111-12 of the Public Health Code in France:

> When a person, in advanced or terminal phase of a serious and incurable condition, whatever the cause, is unable to express his or her will, the doctor has the obligation to inquire about the expression of the will expressed by the patient. In the absence of advance directives mentioned in Article L. 1111-11, he or she shall take the testimony of the trusted person or, failing that, any other testimony from the family or relatives.

The situation in France is therefore quite different from the Anglo-Saxon medical world where the family is generally called on for a decision in the place of a patient who lacks decision-making capacity. Yet, when doctors consult a patient's family member about the patient's wishes, the discrepancy between the patient's wishes and those of his or her family must be remembered. Also, even where the patient does have advance directives, it is not so easy to anticipate future contingencies when writing such advance directives (11), and the presence of some degree of cognitive impairment makes this task even more difficult. Furthermore, when families

are called upon to interpret the patient's wishes, they are sometimes traumatized by the patient's experiences, and communication problems between healthcare professionals and family members often arise. (12)

In a study was found that 46% of respondents perceived conflict during their family member's stay in the intensive care unit, mainly due to communication problems or perceived unprofessional behaviour (such as ignoring the primary caregiver in treatment discussions); 48% of family members reported the reassuring presence of the clergy, and as many reported that their attending physician was the preferred source of information and comfort. Jean-Jacques Kress points out that healthcare professionals have great difficulty both in communicating about the end of life and agreeing among themselves in the first place, and therefore they have difficulty offering a coherent representation of their actions to families (oral exchange).

Thus, family-centered care (13), Davidson & al. 2017) (14) –e. g., empathy shown towards a patient's family members, supporting them, communicating to them certain information in relation to the patient, ensuring freedom of visits– can be a decisive way to facilitate obtaining implicit consent from a patient with the help of family members or, in patients assessed not to have decision-making capacity, to foster agreement between healthcare professionals and families regarding a beneficial decision on behalf of the patient.

It must never be forgotten that families are living in a time of anguish. Present without being able to save their loved one, family members are in a difficult in-between time, being, on the one hand, on edge while awaiting their loved one's approaching death, and on the other hand, being strained by exhaustion as the announcement of death arrives all too slowly. This is particularly true when continuous sedation until death of the patient is implemented. Sedation is often presented as an «ideal beautiful natural death», without pain, without shortness of breath, without visible agony,

without railing, without anxiety, and a death that is de-medicalized. This is, however, an illusion of a «good death», since it remains totally under medical control. Sedation makes the patient powerless and unable to express to anyone his or her experience. It also makes the family impatient that «all may be over soon», generating in them mixed emotions of guilt and desire for a quick end to the patient's suffering.

b) Caregivers who are not family members

The work of caregivers can be essential to support patients who lack decision-making capacity to contribute to healthcare decisions and to provide assent. These caregivers are close to the patient, and they often know what is going on now with the patient, while families know only what happened before.

When a patient without advance directives can no longer express himself or herself, or because he or she is in between moments of drowsiness and lucidity, it is often such caregivers who first recognize the signs of a possible unreasonable obstinacy of treatment. Their proximity to the one whose care involves bodily intimacy almost always makes them able to feel empathy with and solicitude for the patient.

This proximity, however, can sometimes be exhausting. When a patient suffers, when communication among doctors, the patient, and family members becomes conflictual, when caregivers feel that their employers no longer support them, they risk distress and burnout that is harmful to everyone. These precipitate hasty and premature decisions or can result in presuming assent given by the patient where there is none at all.

It is therefore important to promote the well-being of caregivers as much as possible. It also means being as clear as possible regarding the ineffectiveness of treatment (15). Reminds us of the relevance of a theology of failure here.

3. Clinical Situations

While consent forms the «nucleus» of a patient's exercise of autonomy, there can be ethical complexities surrounding obtaining consent for treatments at the end of life. Obtaining consent might be difficult or impossible in certain situations. Let us look at three situations.

Case 1: Withdrawing or limiting treatment of a conscious patient

In this case, how does the healthcare professional inform the patient of such a decision? Can we stop or limit treatment without informing a patient who is more or less conscious and able to communicate? And about what should the healthcare professional inform this patient? In theory, it is easy to say to the patient: «If we continue, we are in an unreasonable therapeutic obstinacy. So we must stop everything». In practice, it is not that simple. What does the message about stopping or limiting treatments mean to the patient? What if he or she does not want to be informed? Article L. 1111-2 of the French Public Health Code states:

> A person's willingness to be kept in the dark about a diagnosis or prognosis must be respected.

It is not easy to determine, however, whether the patient wants to know this information or not: this requires repeated communication with the patient and the possibility of a patient's opinion evolving during the progress of his or her disease. The limited time allocated to care activities, and the hyper-specialization of medicine and fragmentation of care confounds considerations regarding who discloses what information to the patient. There can be a great temptation just to assume that the patient does not want to be informed, especially concerning information that is so difficult to live with existentially for the patient, such as disclosure that he or she lacks decision-making capacity and/or is near death.

Should we ask whether the message about stopping or limiting treatment is «useful» information that can help the patient in his or her personal maturation through this end-of-life experience? The patient can only consent to what he or she understands, but what exactly does he or she understand? That there's nothing more to do? That he or she is going to die soon? That his or her last chance at survival has now passed?

Is there not an obligation for the doctor, with support from the patient's family members and other caregivers, to give priority to a message to this patient that links non-abandonment and maintaining the patient's trust, on the one hand, and withdrawing treatment or even implementing «continuous sedation until death» (as the Claeys-Leonetti law in France permits)?

In the latter case, it will also have to be explained that sedation will definitively cut off communication by the patient and, once sedated, the patient will no longer be able to make requests. «How do I tell the patient that he or she is communicating for the last time? How can we tell the patient that he or she will certainly be present, but at the same time, absent?» (16). Not to mention, that «death, however predictable, is [often] not desired. What do we know about life under sedation? What do we know about dying and dying under sedation? […] How can we talk about 'the unspeakable and the unpredictable' (17), (16).

Residual uncontrolled physical symptoms, added to existential, psychological or even spiritual suffering, can really lead to immense weariness of life and contribute to an unbearable manner of existing. Dementia that sets in gradually can also be frightening. Healthcare professionals and/or family members surrounding the patient are also imprisoned in immense weariness. In these situations, is the patient really free to give consent? Is not he or she simply lacking any option that is better? One cannot be ethically satisfied with a consent that is a vague assent to limited healthcare options.

On the other hand, what if the patient refuses to limit and stop care? Can the doctor dispense with the patient's refusal on the grounds of «medical reasons»? It is certainly necessary to organize a meeting to discuss such reasons with the patient, but the physician should recognize the progressive nature of consent and incorporate this understanding more in his or her relationship with the patient, without expecting the patient's consent in one meeting. Indeed, seeking consent is part of a process of communication based on mutual trust, empathy, and on real pragmatic and interpersonal support, especially when the patient has cognitive impairments.

More and more, however, healthcare professionals find it difficult to converse with patients on this topic and clearly describe situations and decisions. Service d'aide médicale urgente (SAMU, Acronym for Service d'aide médicale urgente: Emergency medical assistance service) and intensive care units in France speak now about «remarkable patients», a euphemism for «do not resuscitate» (DNR). Forgoing resuscitation may be considered by doctors in cases of advanced and progressive serious illness, but should it not be discussed with the person concerned first? During a symposium on medical decisions at the end of life held on April 8, 2019 at the Georges-Pompidou European Hospital in Paris, however, the confusing story of such a «remarkable patient» was told, illustrating the limits and questions surrounding this term (18). Reports the facts for *Libération* in this way:

> It is the story of a man who has been suffering from a degenerative disease for more than 20 years. Recently, he has had another respiratory failure crisis. He is exhausted, tired, but he has not made any decisions about the rest of his life. This time, he gets away with it and can go home. The hospital's doctors, given the seriousness of this man's clinical situation, nevertheless decide to hold a team meeting on the continuation of his care. Strangely enough, the family is not kept informed, but a few days later, they receive a letter that leaves them stunned. They learn that it has been decided that, if the patient returned to the hospital urgently, he would not be resuscitated, and that a long and continuous

> sedation until death would eventually be initiated. Finally, the patient is reported as a «remarkable patient at SAMU», so that the «procedure in case of new respiratory complications» is respected.

This is neither legal nor ethical. The team meeting to forgo treatment cannot legally be held in advance of a future health crisis! The patient must consent at the time of the crisis, if capable, or he or she may stipulate advance directives for when he or she lacks decision-making capacity.

Case 2: When the patient is unconscious and has no advance directives

The Vincent Lambert case in France illustrates all the ups and downs of this situation. On September 29, 2008, Vincent Lambert, 32, had a road accident that caused a head injury which plunged him into a vegetative coma from which he emerged to a state of minimal consciousness, but he seemed to have relapsed later. Despite rehabilitation, there was no improvement. On April 10, 2013, his doctor concluded that he was a victim of «unreasonable therapeutic obstinacy» within the meaning of Article L. 1110-5 in France and decided to stop artificial feeding and to reduce Vincent Lambert's hydration.

Lambert's family, however, was divided: on one side was his wife Rachel and six of his brothers and sisters, and on the other side, his parents Pierre and Viviane and two of his siblings. Rachel argued that Vincent, who was a nurse, had always refused obstinacy while he practised his profession. His parents, very devout Catholics, argued that their son was not at the end of his life, and that he must not be killed. Thus, for the past 11 years, there have been multiple experts summoned to trials, passing through different courts, the Council of State (2014, 2017, 2019) and even the European Court of Human Rights (ECHR) in Strasbourg (Grand Chamber in January 2015 and 3 appeals for review of this decision, all rejected). The procedure for discontinuing care was confirmed by the Chalons Administrative Court, confirmed by the

Council of State and the ECHR in 2019. All these decisions were in the same direction, namely: because of the severe cerebral atrophy and the many injuries observed by multiple medical investigations, «the maintenance of care and treatment constitutes an unreasonable obstinacy because they only have the effect of artificially maintaining the patient's life». (This is the official legal definition of unreasonable obstinacy in French law. It means that the patient is not necessarily at the end of his or her life). On the other hand, «Vincent Lambert's desire not to be kept alive, in the event that he is in such a state as he has been in for ten years» is established. In despair, his parents have appealed to the United Nations' Committee on the Rights of Persons with Disabilities. But is Vincent Lambert a disabled person? Finally, the French Government recalled that it is not required, under international law, to wait for the decision of the UN Committee on the Rights of Persons with Disabilities.

Vincent was hospitalized for 11 years to keep him alive. His wife was his legal guardian but did not have a say in this decision. It was impossible to reach a negotiated consensus within Vincent's family. What should have been done? Should the law have introduced a hierarchy, giving priority to the wife over the parents? A bill to this effect was introduced by Olivier Falorni, Member of Parliament for Charente-Maritime, on May 24, 2019. The MP explained the same day on France Bleu (radio) that a wife is the one with whom we have voluntarily lived, i.e., the spouse or partner, who takes precedence in terms of making decisions for us over any adult child or children, parent or parents. This is because we choose our spouse; we do not necessarily choose our parents.

There is the further question of who should have paid for the continued care of Vincent Lambert. It is not a question of financially evaluating the worth of a man's life. Most, including the Catholic Church, recognize that continuing artificial nutrition and hydration in the context of «unreasonable obstinacy» is, in principle, not desirable because this situation places burdens on the pa-

tient that can be disproportionate to therapeutic benefit for this person at the end of life (see Canadian Catholic Bioethics Institute and International Association of Catholic Bioethics) (19). Distributive justice, then, also becomes an issue when healthcare resources are limited. In pursuing treatment that is morally optional, fewer resources would be available for other forms of necessary health care, for instance, primary care for children and youth.

The case of Vincent Lambert was ethically assessed differently by certain Pro-Life groups and by some bishops. For them, it was a question of disrespecting the inviolability of human life. These depicted patients dying from hunger and thirst as a result of withdrawing artificial nutrition and hydration in films and other media.

Finally, the Cour de Cassation overruled an appeals court which had directed doctors to keep Mr. Lambert alive pending a review of his situation by the UN Committee. On July 2, 2019, physicians removed his hydration and nutrition while sedating him. Vincent Lambert passed away on July 11, 2019. In order to avoid possible appeals, the Reims public prosecutor announced, on the same day, the opening of an investigation into the causes of death and commanded an autopsy.

A joint declaration of religious leaders –rabbi, imam, pastors, bishops– from Reims (France), the city where Mr. Vincent Lambert died, on July 11, 2019, brought some peace:

> …We unreservedly recognize that it accords with the dignity of every human being to refuse treatment deemed unnecessary, disproportionate or likely to cause additional suffering, as long as such a decision does not endanger the lives of any other person... We would like to remind our fellow citizens that becoming dependent on others for care or for the acts of ordinary life does not mean losing their dignity... We express our confidence in the doctors of our country. Our collective trust in their collective scientific and human capacities is necessary so that they can continue to make the best and wisest medical decisions by engaging in a genuine dialogue with people at the end of their lives or with the relatives of people who have become unable to communicate...

Fortunately, not all cases are so ethically divisive and controversial. In this situation, applying the principle of respecting autonomy is not enough. The purpose of care must also be considered, i.e., whether it is for the good of the patient. Hence, the principle of beneficence must be applied. The question immediately arises, however, of under what conditions beneficence is not paternalism? It must be accompanied by «solid safeguards» as we noted above, following Manuel Wolf.

In acting beneficently, however, might healthcare professionals *not* involve family members of the patient? What should they solicit from family members? Can a court decision be imposed in the event of family disagreement?

Case 3: When the patient knowingly refuses treatment(s)

It is very difficult for a patient who is incapable of making decisions to express his or her refusal of treatments. Very often both the family and the healthcare professionals agree to affirm that such a patient has not understood what is at stake.

To fully understand the issues, let us reread the testimony of the well-known German theologian (20), who has just published, with his wife Irene, a book entitled *Sterben und Lieben (Dying and loving)* on their experiences. Irene Mieth had severe back pain and a rapid decline in general condition, which led to an unexpected diagnosis of metastasized breast cancer. In addition to high-dose analgesia, surgical stabilization was quickly needed. As Dietmar sought further medical advice and innovative treatments, however, his wife wrote advance directives in which she refused any medical intervention (no artificial nutrition, no respirator, no dialysis, no antibiotics, no blood transfusion..., only an effective analgesia even if it would shorten life and, if possible, home care). Dietmar accompanied Irene through this dark period but did not understand why she refused the recommended treatments. He wrote that he him-

self would have made a different decision. Yet he supported the decision of Irene, who died six weeks after the diagnosis. It took him a year to understand it. This situation illustrates a refusal of consent which Irene was able to voice, which was attended to and for which she assumed full responsibility. This allowed her free wishes to be recognized, and for both spouses to enter into a dialogue that was unique in its profoundness. (21)

Refusing treatment, however, is not always experienced so positively, especially in the case of patients who are deemed to lack decision-making capacity. When patients refuse treatments, this can sometimes deeply hurt family members who might consider such refusal as masking suicide or abandoning the family, especially when the patient still has young children.

Refusing treatments does not necessarily mean refusing all care. A patient's refusal should lead to a dialogue in truth to better understand the implications of such refusal, to try to identify what the patient refuses, and to contextualize the refusal. Is it due to a lack of understanding? Does the refusal lack clarity? Is it a demand, with pressure placed on someone else to abide by it? Has the patient been influenced, and to what extent, by his or her family members, by religious or cultural affiliations, by fears and anxieties linked to certain representations of treatment, by «undigested» memories in connection with known persons, or by the *nudging of* society (22) aimed at reducing health care costs?

A patient who is deemed to lack decision-making capacity might not be able to express rational arguments but might tear out all medical tubes and devices. Repeated behaviour of this kind should lead to questions regarding such interventions because this behaviour might be equivalent to words. A patient with dementia who refuses all of a sudden to be nourished, in the absence of medical reasons, could also be expressing his or her will.

The refusal of therapy should not lead to a break-up of the healthcare relationship or therapeutic alliance. As was recalled in

CCNE's Opinion N° 87 already mentioned (14 April 2005), doctors must not be satisfied with decisions that are too rapid, immature or uninformed. Pierre Hum and al. also speak of «disguised consents»: the ideal of unconditional and definitive consent, or conversely, an agreement that is too thin, unclear, constrained or abstract. The authors point out that a patient's consent to or refusal of treatment is «always partial, evolving and subject to relational dynamics» (23). This is an important point because it is in trusting relationships that a patient's consent or refusal can be expressed, interpreted by those who know the patient, and ultimately respected.

However, this therapeutic alliance, negotiated after a patient has made an informed decision to refuse treatment, remains fragile, particularly because of medical hyper-specialization and because relatives or other caregivers might not understand the patient's decision to refuse treatment. Relatives can feel totally confused. They might feel deprived of the help and support they wanted for the patient, their loved one, to survive. Instead, the health team is supporting the patient's decision to stop fighting death. How can we support these relatives who are unable to understand the patient's refusal of treatment? Dietmar Mieth talks about the faith shared with his wife and about the spiritual resources that he drew from Meister Eckhart. No doubt everyone must find people to talk to, readings, and spiritual nourishment. In the Abbott study mentioned above, 48% of family members reported the reassuring presence of clergy. This is no coincidence.

It should not be forgotten that, despite Dietmar Mieth supporting his wife's decision, it was only one year after her death that he understood it. In the foreword of his book he notes:

> Now, after more than a year, I know what she meant. Because in her arms, I can't die like she died in mine. Nevertheless: to love, even in weakness, is always a warm and beneficial cloak, which hope and faith put on our shoulders.

Conclusion

Many other issues could be addressed relating to consent for end-of-life treatment. Perhaps one of the most important is how the representation of death affects the reception of information and consent, according to the different actors involved in this process. How is end-of-life decision making influenced when death is represented as frightening or by the illusion of a calm and «natural» good death through sedation or by the promise of a good death through stopping or limiting treatment?

But also: what happens to consent in view of medical hyper-specialization and fragmentation of care among different healthcare structures and different healthcare professionals? For example, an elderly person who in a nursing home shows signs of a stroke and is admitted to the emergency room, sees the radiologist and a host of other healthcare professionals who might not be interested in her as a person but in parts of her body. Because she is assessed to lack decision-making capacity, the neurologist decides to transfer her for neurosurgery, but she dies on arrival. The various investigations performed on her, good in themselves, were probably not adapted to the situation of this elderly person who finally died surrounded by medical technology but without the personal supports that she needed.

Respecting a patient's contribution to the decision-making and consent process is in keeping with respecting the autonomy and dignity of the person, especially when this person lacks decision-making capacity. The end of life, however, often involves ethical complexities surrounding decision making and consent, which this paper illustrates. Becoming aware of this contributes to a greater commitment to respectful and caring healthcare relationships in which patients are involved in making decisions and giving consent as much as possible throughout the care process.

Bibliographic references

1. CCNE, French National Consultative Ethics Committee. Opinion N°87. Treatment refusal and personal autonomy. 2005 Apr 14. Available at: https://www.ccne-ethique.fr/en/type_publication/avis?page=5 https://doi.org/10.1007/s11019-016-9724-3
2. Veshi D. Comments on the Lambert case: the rulings of the French Conseil d'État and the European Court of Human Rights. *Med Health Care Philos.* 2017 Jun; 20(2): 187-193. Wikipedia. Affaire Vincent Lambert. Available at: https://fr.wikipedia.org/wiki/Affaire_Vincent_Lambert (consulted 2020 Jun 09).
3. Wolf M. Consentement, éthique et dogmes. *Ethics, Medicine and Public Health.* 2015 Jan; 1(1): 120-4. https://doi.org/10.1016/j.jemep.2014.12.002
4. Hennette-Vauchez S. Disposer de soi? Une analyse du discours juridique sur les droits de la personne sur son corps. Paris: L'Harmattan; 2004.
5. Ricoeur P. *Vivant jusqu'à la mort.* Suivi de Fragments. Paris: Seuil; 2007.
6. Ricoeur P. *Philosophie de la volonté I. Le volontaire et l'involontaire,* Paris: Aubier (1950); 1988.
7. Crouch G. Female Dutch doctor drugged a patient's coffee then asked her family to hold her down as she fought not to be killed, but did not break the country's euthanasia laws. *Daily Mail.* 2017, Jan 28. [Accessed 2017, Jul 10]. Available at: http://www.dailymail.co.uk/news/article-4166098/Female-Dutch-doctor-drugged-patient-s-coffee.html»\l«ixzz4mSevx78w
8. Thiel MJ. Introduction. In Thiel MJ, editor. *Entre Malheur et espoir. Annoncer la maladie, le handicap, la mort.* Strasbourg: PUS, 2006; 5-20.
9. Kress JJ. *Éthique en psychiatrie: information, consentement, décision.* In Marie-Jo Thiel, editor. Où va la médecine? Sens des représentations et pratiques médicales. Strasbourg: PUS; 2003; 55-67.
10. Kress JJ. Aspects éthiques du consentement à la psychothérapie. Ann Psychiatr. 1998; 13(2): 85-90.
11. Thiel MJ. Personal Capacity to Anticipate Future Illness and Treatment Preferences. In Lack P, Biller-Andorno N, Brauer S, editors. Advance Directives. Dordecht: Springer. 2014; 17-35. https://doi.org/10.1007/978-94-007-7377-6_2
12. Abbott KH, Sago JG, Breen CM, Abernethy AP, Tulsky JA, Families looking back: one year after discussion of withdrawal or withholding of life-sustaining support. *Crit Care Med*. 2001 Jan; 29(1): 197-201. https://doi.org/10.1097/0000 3246 -200101000-00040
13. Mazaud A. Fin de vie en réanimation: vécu et prise en charge des familles, vécu des soignants. Jusqu'à la mort accompagner la vie. 2019 Jan; (136): 95-106. https://doi.org/10.3917/jalmalv.136.0095
14. Davidson JE, Aslakson RA, Long AC, Puntillo KA, Kross EK, Hart J, Cox CE, Wunsch H, Wickline MA, Nunnally ME, Netzer G, Kentish-Barnes N, Sprung CL, Hartog CS, Coombs M, Gerritsen RT, Hopkins RO, Franck LS, Skrobik Y, Kon AA, Scruth EA, Harvey MA, Lewis-Newby M, White DB, Swoboda SM, Cooke CR,

Levy MM, Azoulay M, Curtis JR. Guidelines for Family-Centered Care in the Neonatal. Pediatric, and Adult ICU. *Crit Care Med.* 2017 Jan; 45(1): 103-128. https://doi.org/10.1097/ccm.0000000000002169
15. Jacquemin D. *Bioéthique, médecine et souffrance. Jalons pour une théologie de l'échec.* Québec: Médiaspaul; 2002.
16. Tomczyk M, Viallard ML, Beloucif S, Mamzera MF, Hervé C. Sédation continue maintenue jusqu'au décès: comment en informer le malade et recueillir son consentement? *Médecine Palliative.* 2015; 14(2): 111-117. https://doi.org/10.1016/j.medpal.2015.01.003
17. Jankélévitch V. *Mort.* Paris: Flammarion, 1977.
18. Favereau E. Attention «patient remarquable». Libération, 2019 avril 9. Available at: https://www.liberation.fr/france/2019/04/09/attention-patient-remarquable_1720079
19. Canadian Catholic Bioethics Institute and International Association of Catholic Bioethics. Reflections on Artificial Nutrition and Hydration. *National Catholic Bioethics Quarterly.* 2004 Winter: 774-782. Available at: https://iacb.ca/wp-content/uploads/2018/06/ANH.pdf https://doi.org/10.5840/ncbq20044410
20. Mieth D, Mieth I. *Sterben und Lieben. Selbstbestimmung bis zuletzt.* Freiburg im Breisgau: Herder Verlag; 2019.
21. Thiel MJ. Devoir mourir au nom de son autonomie. *La Croix.* Mars 6, 2017; 26.
22. Olivier C, Thiel MJ, La fin de vie au risque d'une spoliation de l'autonomie. *Esprit*. 2017 déc. (440): 124-135. https://doi.org/10.3917/espri.1712.0123
23. Hum P, Boury D, Danel T, Demailly L, Dujardine V, Ethuin C, Lequin F, Pruvot FR, Racine A, Valette P, Vandoolaeghe S, Weil B, Weill S. Le refus de soin: forces et faiblesses du consentement. *Éthique et santé*. 2015; (12): 56-63. https://doi.org/10.1016/j.etiqe.2014.09.002