Discontinuing dialysis: patient’s wishes and professional judgement

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Introduction

There are specific moral problems attached to life-prolonging medical technologies, for instance the range of questions about stopping treatment when the burdens seem to outweigh the benefits [1]. Physicians, patients and family do not always agree about the best treatment [2]. A reference to the moral principle of respect for autonomy is often made to solve a controversy [3,4]. In practice, however, the appeal to this principle is less fruitful than is often assumed [5–7].

Here we would like to illustrate that in medical practice the usage of well known medical–ethical concepts, such as autonomy and paternalism, sometimes obscures discussions about moral problems [8,9]. We present the case of a patient who refused to discontinue dialysis on religious grounds while the physicians in charge regarded stopping dialysis as the best option. Initially, dialysis was continued, but when the patient became incompetent the doctors began to consider ending the treatment. The patient finally died because overhydration was intentionally left untreated. At first sight, the decision of the physicians seems paternalistic, but in this article an alternative explanation is offered.

The main problem in the case relates to the fact that the physicians did not share the patient’s religious convictions. This raises the question of whether the explicit wishes of the patient to continue dialysis should have been followed under all circumstances. We will elaborate this question and will argue that the constant balancing of the (supposed) wishes of the patient and the professional judgement of the attending physicians is the most desirable approach, but is not the easiest one. Intensive and regular deliberation among all participants is then required.

Case history

Mr A, born in 1950, had been suffering from diabetes mellitus type 1 from the age of 5 years. In 1989 his eyesight weakened, the sense of touch in his hands and feet decreased, and his renal function deteriorated. A few months later dialysis was started on a schedule of three times for 4 h a week. About 5 years later Mr A began complaining about pain in his right hand. The pain was caused by ischaemia, and the most painful finger had to be amputated. This was the beginning of a months long process which ended in amputation of the greater part of all extremities. In spite of the amputations, he still suffered from severe pains necessitating the use of morphine derivatives.

After the first major surgery on Mr A’s right leg, the attending nephrologist discussed the possibility of discontinuing dialysis with the patient and his wife. Mr A stipulated that the moment and the mode of death were in God’s hands. Therefore, life-sustaining dialysis treatment should continue. Mr A also made it clear that he did not want to be resuscitated. In his view, a heart attack was a sign from God that his time had come. Doctor and patient agreed that intervention in case of ‘emergencies’ was not desirable. This meant that he should not be referred to the intensive care unit.

Following the amputations of his arms and legs, Mr A felt quite well in spite of all his problems. The physicians, however, expected deterioration of his condition with more pain, further amputation, and infection. Three months later this became true as one of the amputation wounds was infected and painful. Surgical intervention did not improve his condition. He became very drowsy and suffered from periods of aphasia, so that conversing with him was no longer possible. The attending surgeons suggested discontinuation of dialysis, but the physicians involved could not reach agreement about what was in the best interest of this patient.

A few days after the last operation, Mr A became short of breath presumably due to overhydration. The surgeons decided to give him morphine and to leave the overhydration untreated. A few hours later Mr A died.

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Discontinuing dialysis

Good medical practice

This case raises at least three moral issues. The first is why the physicians had doubts about the continuation of dialysis and even discussed this with the patient and his wife, whereas the patient never mentioned this possibility spontaneously. Would it not have been more respectful if the physicians had waited until the patient had brought up the subject himself? Secondly, there is the issue of changing circumstances. One can ask whether stopping dialysis would have been in accordance with Mr A’s wishes and religious convictions when his situation deteriorated. How should his remarks about continuation be interpreted? A third issue is the surgeon’s decision to treat Mr A with morphine, where the physicians might have been able to postpone Mr A’s death by treating overhydration with ultrafiltration. These three issues will be discussed in the following sections.

Each of the questions reflects a conflict between respect for the patient’s wishes and convictions of the physicians about the best interests of the patient. The views of the doctors gradually seemed to predominate, especially when Mr A became incompetent. Is the conclusion justified that the physicians went against the wishes of the patient and let their own judgement prevail? Did the physicians treat Mr A in a paternalistic fashion? At first sight, the answer to these questions seems to be quite obvious: a yes. However, after analysing the patient’s history in greater detail, doubts arise. In the following, we will provide an alternative explanation of the decision-making process based on a detailed description of the role of various care providers.

Three moral issues

Discussions with the patient

The attending nephrologist explained that he had raised the issue of discontinuation of dialysis because of the poor prognosis of Mr A. Anticipating the need for decisions in the future, the doctor wanted to know Mr A’s wishes. In the patient’s medical record the following notes were entered: ‘Explained that besides dialysis, ultrafiltration is a possibility. He does not want to end dialysis now’. A few pages further the medical record reads: ‘avoids the subject of ending dialysis. In my view, he is not yet ready for it’. The nephrologist decided to let the matter rest for the time being.

To understand the approach of this nephrologist better, it is useful to have insight into the actual circumstances. The following experience of one of the authors (A.L.) is revealing:

While I am looking at the clumsy movements of his stumps, a sharp feeling of irreversibility strikes me. This man will never cycle or walk, play with his son or caress his wife again. He can not even go to the toilet or wash without help from others.

In addition, his alertness and clarity of mind leave much to be wished. ‘Why don’t they stop dialysis’, I ask myself, ‘this is a terrible life’.

It was clear that the physicians and nurses shared the experience described; they viewed Mr A’s life as agony. Feeling compassion for the patient led the physician to discuss the issue of discontinuation with Mr A and his wife. He mentioned the possibility of ultrafiltration instead of dialysis as a starting point for such a conversation.

As the chart suggests, the physicians thought that the wishes of the patient might change. They were not fully mistaken: occasionally pain and misery during the last hour of a dialysis session caused despair and depression to such an extent that he wanted to terminate the dialysis session an hour early. However, when the doctors proposed a less strict dialysis policy, Mr A did not decide to discontinue dialysis altogether.

Another factor is of importance. The attending nephrologist explained that, in his experience, patients often have great difficulty starting a discussion about discontinuation of treatment and subsequent death [10]. Many are afraid of the suffering and the respiratory difficulties after discontinuation of dialysis. The latter concern can be revealed by informing the patient that the major problem, overhydration, can easily be managed by ultrafiltration. This explanation is usually followed by discussion about the patient’s wishes concerning discontinuation of dialysis and death, and subsequently patients often feel relieved that they had the opportunity to discuss their wishes. To have this kind of discussion with Mr A, however, was rendered difficult by his almost constant drowsiness.

Interpretation of the patient’s words

When the patient was admitted to the surgical ward, the nephrologists were confronted with a dramatic deterioration in the patient’s condition. From their professional point of view, the nephrologists considered further dialysis ‘futile’ since it implicated ‘an extension of suffering without a (chance of) a dignified life’. In addition, the physicians did not share the religious convictions of the patient and his wife about human existence in relation to the continuation of dialysis. As a consequence, questions arose about the role of their judgement and the wishes of the patient.

Patients’ statements about a hypothetical future situation frequently differ from what they actually wish when the real situation arises. This may also have been the case with Mr A. Although he had stated that he wanted to continue dialysis, it remains to be seen whether he would still have insisted upon continuation of dialysis when he was suffering more severely.

Ironically, the physicians’ doubts about the seriousness of the patient’s wishes were strengthened by the patient referring to his religious convictions. They deemed it possible that Mr A considered continuation
of dialysis to be his duty, although his deepest feelings were different. In addition, Mr A’s convictions did not seem to be very consistent to the nephrologists: on the one hand, he wished to continue a life-sustaining treatment (dialysis), but, on the other hand he rejected potentially life-saving options such as resuscitation and intensive care.

Uncertainty about the true wishes of Mr A was exacerbated by an incident that happened a few weeks before his death. He was brought to the hospital by his wife after having vomited a great quantity of blood during the preceding night. He looked pale and was very drowsy. After consultation with his wife, the attending physician decided to provide symptomatic treatment without further diagnostic procedures. Mr A recovered and agreed in retrospect with this approach.

Thus, the physicians were uncertain about the exact wishes of Mr A when his condition worsened. Even in situations when there are no doubts at all about the actual wish of a patient, however, another type of uncertainty remains. A physician’s professional judgement might not be in accordance with the patient’s wishes. The uncertainty raised is one of ‘when to diverge from a patient’s wishes’.

The professional judgement of the physicians in the case of Mr A was directly linked to the physicians’ notion of good medical practice. One of the nephrologists made the following comment:

A professional judgement has two aspects: the first is the medical judgement about, among other things, the prognosis of the patient; the second aspect is the empathy of the doctors with the specific situation of a patient.

Professional judgement is independent of the convictions of patients or families: only the patient’s circumstances play a role, not his beliefs or ideas. However, ‘professional judgement’ is more than judgement on strict medical grounds; in the case of Mr A the physicians were convinced that dialysis and ultrafiltration, although medically possible, had become futile as they only prolonged suffering.

The professional judgement of the physicians, however, did not cause them to stop treatment automatically. Why not? Because their professional judgement was not in accordance with the wishes of the patient. The main question was how professional judgement should be balanced against the wishes of the patient. During the evolution of Mr A’s illness, uncertainty increased concerning the patient’s exact wishes. It appeared that with time the patient’s statements were less and less relevant to the physicians’ decisions about treatment in the terminal phase. Instead, the physicians’ convictions about suffering, a decent life and good medical practice played an ever increasing role in their decisions regarding the treatment of Mr A.

Choice of terminal treatment

The physicians who took part in this case believed that they were not always obliged to continue treatment at the patient’s request. As one of them phrased it: ‘there is a limit on “keeping a body alive”, even if it is in accordance with a patient’s wish’. Reaching this limit was the main reason why the nephrologists largely agreed with palliative treatment as carried out by the surgeons.

Both surgeons and nephrologists were in agreement in their professional judgement: the prognosis of Mr A was very poor, and life-prolonging treatment was futile. The surgeons were guided exclusively by this judgement and did not attach much weight to past wishes of the patient. In contrast, the patient’s past statements weighed importantly on the decisions of the nephrologists. An explanation for this different approach might be that the surgeons met Mr A less frequently. Consequently, they observed a sudden dramatic deterioration in Mr A’s condition that, in their view, justified discontinuation of dialysis. The nephrologists, on the other hand, were guided more by their experience of having watched the process evolve over time.

One of the nephrologists conveyed that, had he been in the position to decide, he would have consulted the family and proposed considering the acute deterioration as an ‘emergency’. Consequently, ultrafiltration would not have been indicated, as the patient had said that life-sustaining interventions should not be started in case of emergencies.

Conclusion

Ethicists sometimes propose that physicians should merely decide about medical–technical aspects, leaving the final decision to the patient or his family [9,11,12]. Professional judgement is independent of the convictions of patients or families: only the patient’s circumstances play a role, not his beliefs or ideas. However, ‘professional judgement’ is more than judgement on medical–technical aspects of treatment, they would never have thought of discussing discontinuation of dialysis. Because it is unlikely that Mr A would have initiated such a difficult discussion, the result would have been that his wishes had remained completely unknown when he became incompetent.

In their decision concerning Mr A’s treatment, the nephrologists chose a middle road; both their professional judgement and the wishes of the patient were elements in the decision-making process. This middle of the road approach prevents physicians from acting too hastily and gives the patient more influence on the final judgement. It necessitates, however, attaching greater weight to discussions with the patient and his relatives about the choice of therapy. We think this middle of the road approach was the most appropriate in this (and probably many other) cases.

Although our first impression was that the case of Mr A concerned a conflict between two opposing principles: respect for patient autonomy and paternalism, this antithesis is inadequate to describe this com-
plex case. The case of Mr A is viewed by the nephrologists not as one of two conflicting ethical principles necessitating making a choice. Mr A’s case illustrates the need constantly to weigh the patient’s wishes and the physicians’ professional views.

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