From curing to caring: one character change makes a world of difference. Issues related to withholding/withdrawing renal replacement therapy (RRT) from patients with important co-morbidities

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Introduction

The widespread availability of renal replacement therapy (RRT), the technical improvements in RRT techniques and the improved survival of patients with associated important co-morbidities, such as diabetes and cardiovascular disease, have led to a situation where, technically speaking, virtually every patient can
be accepted for RRT. It appears that widespread access to RRT has shifted the initial dilemma of which patients should be selected for RRT (positive selection) to the question of which patients should not be initiated on RRT (negative selection). This ethical problem is not only limited to the single patient level (will this particular patient benefit from RRT?), but also relates to the community level, as RRT places an important burden on the health care budget, and choices have to be made in selecting health care priorities in some countries (the problem of sustainable development). In addition, survival on RRT has improved. The majority of end-stage renal disease (ESRD) patients maintain an acceptable quality of life. However, some long-term RRT patients experience a gradual decrease in quality of life, leading to the question of whether RRT should still be continued. Despite the fact that these ethical problems related to decisions of withdrawing or withholding RRT are part of the daily practice of all nephrologists, there are only limited data available on different treatment practices, and their related outcomes. In the USA, for example, the analysis of 2746 deaths showed that in 26% of patients, RRT was stopped before death [1]. However, in only 4% of these patients was uremia indicated as the cause of death, and 30% of patients died <3 days after cessation of RRT, making it unlikely that withdrawing RRT was the real cause of death. In the study of Birmelé et al., published in this issue of Nephrology Dialysis Transplantation, 20% of patients died after cessation of therapy, but in only 6.6% of them was the decision to withdraw dialysis also noted in the files. The skewed distribution of days to death indicates that most patients probably died <5 days after cessation of therapy, again probably pointing to a very poor underlying clinical condition rather than uremia itself as the cause of death. Of the 40 patients, 32 were considered to be too weak to take part in the decision process. All this information points to a dichotomous view on the topic of withdrawal/withholding of RRT, with the question being raised rather late, and the decision process, if discussed at all, seldom being registered. In only four of the participating centres was a systematic open discussion on the decision-making process available.

Although legislative directives differ from country to country, most of them have one common point: they increase the dilemma between the right of the patient to refuse treatment and the obligation of the physician to treat patients [2]. This contradiction is rather easy to solve in competent patients, where most courts will state that the right of a well-informed patient to refuse treatment prevails. In incompetent patients, however, this situation leads most physicians and family proxies to continue RRT, even if it appears futile to them, out of fear of being taken to court by another family member. This hypothesis is supported by the observation that physicians with a background in bio-ethics and/or legislation appear to have a higher rate of withdrawal/withholding than those who did not have these specific skills [3].

Economic arguments can, without doubt, be ethically acceptable in developing countries where other health care priorities save more lives. Most of us would feel that this does not apply, however, to highly developed countries such as Europe, the USA or Japan. Nevertheless, also in developed countries, ethical choices are inevitable. The problem is not strictly financial, but also concerns the self-perpetuating system of infinite patient needs and rising expectations, and the further development of medical technology. For this reason, it can be accepted that, at a certain level, economic aspects are considered in the decision-making process [4], and this may explain the strikingly wide difference in acceptance rates and in co-morbidity of the RRT population in different countries, pointing to a ‘socially accepted numerus clausus’ in some countries.

It appears that the discussion to start/withdraw RRT is blurred by differences in personal opinions of the different players, some grey-zone legal aspects, and economic considerations. It thus comes as no surprise that treatment practices among nephrology centres differ widely [5–7]. All these considerations mean that physicians prefer a ‘technical’ rather than a ‘bio-ethical’ approach to the problem, as this avoids ‘slippery slope’ discussions, within the renal team itself as much as in the relations with the patient and his family, and with regulatory authorities [8].

In the following, we attempt to provide convincing arguments in support of our opinion that such an attitude does not facilitate final decision making, and may finally lead to suboptimal care.

**Decision analysis: to treat or not to treat**

One solution might be to opt for strict guidelines on which patient groups should be denied access to RRT. This practice was accepted in the early years of dialysis, and has prevailed for a long time in countries such as, for example, the UK, where the availability of RRT was limited. From an ethical point of view, denying patients dialysis on the basis of a common denominator such as age, gender or social class is considered as an unethical practice at present, because it is a form of discrimination. In the USA for instance, it has become apparent that the distribution of patients on RRT does not represent that of the whole ESRD population, and that, for example, blacks and females are under-represented [9]. Even if the grouping tag is based on a clinical condition (e.g. diabetes or age), this approach remains disputable. First of all, it is hard to categorize the clinical condition of a patient in a scaling or denominator system [10]: a 70-year-old diabetic may be in relatively good general condition, whereas a 60-year-old cardiovascularly compromised patient may have a far worse prognosis. Using ‘group’ as a decision criterion, most would start RRT in the latter, but not in the former. This can lead to denial of RRT in patients who might have benefited from it,
whereas RRT could be initiated in a patient in whom it would have been better not have started. In addition, it was demonstrated that in a group of octogenerians with ESRD, social isolation and late referral were far more important in the decision not to start RRT than parameters such as diabetes or Karnofsky score [11], indicating once again that these so-called ‘objective criteria’ used to initiate or withhold RRT do not work.

About curing and caring

Most physicians consider ‘curing’ as the most important aspect of their task, partly because they are well trained in the matter. In addition, for most ‘technical interventions’, there is available evidence on (measurable) outcomes, avoiding the need for ‘personal involvement’. In view of the Hippocratic oath that physicians should act to preserve the life of their patients, this leads to the comfortable position where the optimal treatment is easy to choose: if under condition A, B and C, treatment X results in a better survival/cure than treatment Y, X is the preferred treatment. This ‘mechanistic’ approach only works for ‘mechanistic’ problems, and completely fails when ‘quantity’ and ‘quality’ of life are not in agreement, because it does not allow personal preferences of the patient and/or the relatives. If the patient suffers from ESRD, the only ‘cure’ is to start RRT. This, however, has not answered the question of what is ‘good’ for this patient. If in the latter situation, the physician continues to use the ‘curing approach’, he will have the choice either to take a paternalistic view (I know what is best for you), or explain all technical details in an unbiased manner to the patient and the relatives, leaving the final decision to them. In the study of Birmelé et al., it appears that in many cases, the paternalistic approach is used. Note that both ‘withdrawal’ and ‘withholding’, the most used denominators in this discussion, consider the problem from the point of view of the physician as a decision maker, and are thus in fact already a reflection of a hidden paternalistic approach. This approach starts from the wrong point of view that the care giver has much more knowledge and experience in the field than the patient. As this is clearly true for the technical treatment aspects, it is also evident that the person who knows the patient’s personal feelings best is the patient himself, or his relatives. The technical knowledge of the care giver thus does not imply automatically that he is empowered to take decisions on other peoples’ lives. In addition, in these cases, decisions might be biased by unconscious prejudices regarding the ‘social value’ of the patients (or their relatives) at hand. Many would therefore advocate that the decision should be taken by the patient or a relative, after appropriate information on the different treatment options and their expected outcomes. Although this approach would appear to be preferable from an ethical point of view, it might become a Trojan horse if it is implemented as a ‘hang yourself’ approach, placing full responsibility and the potential feelings of guilt associated with them on the patient, and especially the relatives. This approach relieves the care giver of the task of making a decision, but can induce a profound feeling of guilt in the patient, making him/her decide to withdraw dialysis because ‘he/she is just a burden to his family and society’, or the relatives, who decide to continue RRT, out of fear to have ‘terminated the life of their loved one’. In most cases, therefore, the ‘curing’ approach will result in suboptimal treatment from a qualitative point of view.

It appears to us that a deliberate switch from ‘curing’ to ‘caring’ might solve many of the ethical and legal considerations, and in addition smooth the relationship and discussion with the patient and their relatives [12,13]. ‘Curing’ implies a technical action that in some way prolongs the life of the patient, or improves some physical problem. ‘Caring’ implies the holistic process whereby the patient feels comforted by the treatment, and relates more to ‘quality’ than to ‘quantity’ of life. For most patients in whom appropriateness of RRT is a point for discussion, no real ‘cure’ is achievable. A ‘curing’ approach can in these circumstances induce a feeling of being abandoned (nothing can be done for me) in the patient, and a feeling of failure in the care giver. This might lead to the initiation of RRT as a surrogate therapy, even in patients where no benefit from the therapy can be expected, or to a complete disruption of the relationship with the patient out of a feeling of shame. It is without doubt that in no circumstance should the patient be given the feeling that he will be abandoned, or that ‘nothing’ can be done. In contrast, by taking the ‘caring’ approach, it will be clear to the patient that, in whatever circumstance, whether on RRT or not, a competent person will take care of his problems. Also for the care giver, this caring approach has its rewards, as it always gives the opportunity to do ‘something meaningful’, even if this is not a medical intervention with a defined or measurable outcome. It is of note that most physicians understand the Hippocratic oath as a promise to ‘do no harm’, whereas the original Greek text uses the positive expression: ophelein, which in fact means ‘to benefit’. In this view, helping the patient to make his last days on earth comfortable is in total agreement with a caring view in the task of a health care worker. In contrast, the negative translation do no harm can lead to the misunderstanding that everything should be done to avoid ‘wrong’ to the patient, and thus to prevent him from dying.

The ‘caring’ approach shifts the focus from ‘quantity’ to ‘quality’ of life. As quality of life is a subjective matter, it is not easily converted to ‘objective’ scores. It is therefore quite hard to relate different treatments A, B or C to different outcomes X or Y. The final outcome will always depend on the weight of the priorities of various factors for the patient. To solve the problem, the physician will have to listen to the patient to determine these priorities. During this process, the care giver should take care
not to mistake his own perception of the patient’s quality of life with that perceived by the patient himself. Many patients appear to reduce their demands on quality of life together with their decreasing physical capacities, and many patients have accepted conditions that we as healthy persons would consider as unacceptable [14,15]. In this view, it is striking that in a French study [11], only six out of 107 octogenarians who were offered RRT refused the treatment. Also, Cohen et al. found that most patients on dialysis had never considered stopping dialysis [16]. The task of the care giver in this type of decision process is substantial, time-consuming and most often emotionally demanding, as he will have to reformulate the patient’s expectations, fit them into the available technical possibilities and come up with a solution that is satisfactory for the patient. It is thus no surprise that most physicians tend to avoid these discussions with their patients [16], pretending to be too busy with the technical struggles of daily life. Once again, it is very important that the patient realizes that all options are valuable, and that, whatever decision is taken, the care-giving team will support him further to maximize his quality of life. This ‘right of care’ is a fundamental right of the patient, and should be the main concern of the care-giving team [17].

A caring approach with a trial of RRT

A major obstacle is that most patients have difficulties grasping the experience of RRT, with its related benefits and drawbacks. In some cases, the physical condition of the patient may improve after starting RRT whereas, in others, it may even worsen due to RRT-related complications. A caring approach, with a well-balanced picture of the individual situation, will most often result in a trial of RRT. Although it seems reasonable to give the patient the benefit of the doubt, it appears that most physicians prefer withholding to withdrawing RRT [18], probably because this is, at least from their point of view, psychologically less demanding. As to cessation of treatment, balanced and calm information on ‘death from uraemia’, and the available ‘supportive measures’ can comfort the patient, and make the decision easier, and more acceptable, also for the relatives. Death from terminal uraemia comes relatively quickly, mostly within 1 or 2 weeks, and is considered by most as a ‘gentle’ death [19,20]. The knowledge that cessation of therapy is possible, acceptable and feasible at any moment, and that the care-giving team will support this decision at any time also makes it more tolerable for the patient to try RRT for a period of time. Once again, the knowledge that something can be done is of extreme importance for the mental well-being of the patient. The practice of offering a trial of dialysis supposes that clear options are available on how and when the trial will be evaluated. Some patients who do not improve with dialysis appear to feel ‘too good to die’ but ‘too bad to stay alive’. In this kind of situation, clear treatment goals should be negotiated with the patient or the relatives before the start of RRT [5].

If the patient is too sick to benefit from RRT, the final decision will be a self-fulfilling prophecy. If the patient experiences the benefits and burdens of the treatment as unacceptable, the caring emphatic care giver will pick this up, confirming once again to the patient that he will be cared for even after cessation of RRT.

A caring approach to withdrawing RRT in chronic RRT patients

Patients already on RRT for a long period of time should be considered as a special subgroup. Especially for these patients, the rule must be that communication should be considered as occurring between two equal partners, since the patient has already gained experience with RRT and its merits and drawbacks. Especially for this patient group, the back-up of ‘a gentle death’ should be made available as an option when their general condition is deteriorating. This issue can be addressed directly with the patient when he is still competent, by asking for value-based directives (under which conditions would prolonging your life by RRT be unacceptable to you?). Of course, this question should be asked several times, preferably phrased differently [21]. Also, once again, they should be reassured that dialysis withdrawal results in a peaceful, pain-free death, and that the commitment of the health care team remains until the end of the process.

Conclusion

The question of ‘withholding or withdrawing’ dialysis is essentially part of a much more important and fundamental question, namely: what should be the ultimate goal of medicine and health care workers. The exponential growth of our technical skills and knowledge on biology in general and medicine in particular has given the impression that the human body is a machine that we can cure indefinitely. We are able to use organs from brain-dead donors whose heart is still beating to replace malfunctioning organs in others. We can keep alive people who have stopped breathing by mechanical ventilation. We can read the DNA of patients, and in the near future we will probably be able to alter it to cure diseases. Meanwhile, thousands of people are dying because they lack clean drinking water or adequate nutrition, or because they have no money to pay for medication for worldwide disastrous diseases such as malaria. Our expanding technical know-how on medicine has brought us to the position of Prometheus, reaching for knowledge we might not be able to handle properly. Some of us might regard the introduction of economic, legislative, philosophical and religious aspects into the daily routine of our
medical behaviour as a punishment for this knowledge [6]. Others might argue, however, that the consideration of all these aspects makes the distinction between a technician and a physician, and that sound ethical decisions on all these matters should be borne by the understanding of the health care worker of his real task: not only curing, but also caring about patients who have put their trust in him.

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References

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