

On discontinuing dialysis

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Author's abstract

Ethical issues relating to the withdrawal of dialysis are discussed, comparing dialysis with other life-support systems, particularly artificial ventilation. It is argued that there is no ethical difference between discontinuing treatment in each case. One practical difference between the two is that patients with chronic renal failure are less likely to have reduced autonomy, and so can engage in discussions with their doctors regarding the situations in which their life-supporting treatment might be discontinued.

It is argued that doctors caring for patients on dialysis have an ethical duty to discuss with these patients the circumstances in which they may wish to discontinue dialysis.

Chronic haemo – or peritoneal – dialysis is a treatment for patients with terminal renal failure which replaces the function of the kidneys and so keeps the patient alive. Thus dialysis is a life-support technique that is on a par with artificial respiration for patients who have respiratory failure, or enteral or parenteral nutrition for those who cannot feed themselves adequately. Discontinuation of dialysis for a patient who has chronic renal failure leads as inevitably to death as does turning off the respirator of someone who is dependent on artificial respiration, or ceasing to feed someone in a persistent vegetative state.

Chronic dialysis became established as a treatment for End-Stage Renal Disease (ESRD) in the late 1960s and early 1970s. Since then, and particularly in the 1980s, the criteria for accepting patients onto dialysis programmes have become more open, with more elderly patients, as well as patients with concurrent diseases, being accepted. At the same time the original population of (relatively young) dialysis patients has grown older. Because of the high incidence, and faster progression, of atherosclerotic arterial disease, as well as more specific complications of chronic renal failure, the chronic dialysis population includes increasing numbers of

disabled as well as elderly patients. As a result, some patients have a deteriorating quality of life while being kept alive by dialysis, while others suffer concurrent illnesses. Both of these factors may bring into question the appropriateness of continuing dialysis treatment.

Studies of the cause of death in dialysis-dependent patients have reported withdrawal of dialysis as the cause with a frequency varying between 4 and 22 per cent of all deaths (1). These patients are reported to be on average older, and to have a higher incidence of diabetes and diabetic complications, and vascular problems, than the overall dialysis population. In most cases the possibility of discontinuing dialysis was raised by the patient and/or her family. In the 'vast majority' of cases the patients were mentally competent. Another study has reported that elective discontinuation of treatment was more common in home, rather than centre (hospital), dialysis patients (2). In that study, a retrospective survey of the relatives of patients who had died in this way reported that social workers and nurses, but not doctors, had been helpful during the time of the patient's decision-making and death. Indeed none of the respondents had thought that doctors had been of particular help, and one had said the doctors were evasive, unreasonably optimistic, or difficult to contact. The stress of the procedure (considered greater for home-dialysis patients) was cited as a major reason for wishing to discontinue treatment. Playing down this aspect of treatment by doctors may have contributed to their involvement being reported in such a negative way.

Other writers have emphasised the possibility that psychiatric disorder – ie clinical depression – may underlie a patient's decision to stop dialysis (3). This may be of particular concern in view of the frequency of clinical depression in patients with chronic illness, and the frequency with which the diagnosis is overlooked. In two-thirds of the deaths reported by these authors to have followed an active decision to stop dialysis, that decision was initiated by the staff, rather than the patient.

Patients who are dependent on a respirator do not usually have this life-support treatment withdrawn unless they fulfil strict criteria for brain death (although other essential treatment – such as drug treatment, for example with antibiotics – may be

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withdrawn if considered physiologically futile). The same criteria are not usually applied to withdrawing dialysis.

In this essay I shall examine some of the ethical issues involved in the discontinuation of dialysis. I shall attempt to determine whether there are any good ethical reasons for treating the discontinuation of these two life-support treatments in different ways, and to put these issues in the context of the guidelines on decisions to forgo medical treatment that were reached by the Appleton Consensus (4).

It might be suggested that the difference between switching off a respirator and discontinuing dialysis is the difference between killing and letting die, or the difference between an act and an omission. Thus, for a patient on a respirator the decision that has to be taken is whether or not to turn off the respirator, while for a patient receiving intermittent haemodialysis treatment the decision is whether or not to initiate the next dialysis session. Similarly, for a patient on peritoneal dialysis the decision is whether or not to initiate the next exchange of dialysis fluid.

Seeing the question of discontinuation of dialysis in this way makes it exactly analogous to the approach taken by Kennedy (5) to the question of turning off a respirator. He argues first that the moral dilemma can be solved by arranging that the respirator is off when the decision has to be taken, and then that the doctor may be 'entitled to desist from returning him to the respirator ... the ethical question thus becomes not one of turning off the respirator but rather of turning it back on again'. This argument has been effectively countered by Harris (6), who points out (as does Kennedy in a separate strand of argument) that the crucial issue is the effect the respirator's being on has on the patient. If it is good, then the respirator should be on, and if not, it should be off, irrespective of whether the respirator happens to be on or off at the time the decision is made.

That this is the case can perhaps be seen even more clearly if one imagines a situation in which each breath of the respirator had to be separately initiated by a doctor. It could not then be argued that this made the ethical issue of discontinuing respiration by failure to initiate the next breath a different one from that if the discontinuation was brought about by switching off the respirator. Turning then to haemodialysis, the fact that the treatment is intermittent, and so may be discontinued between active treatment sessions, is not a relevant difference from the switching off of a respirator. Finally, there are forms of renal-replacement therapy used in intensive care units that are continuous, rather than intermittent, such as continuous arterio-venous or veno-venous haemofiltration or haemodiafiltration, and it is hard to accept that discontinuation of those forms of renal-replacement therapy could involve different ethical issues.

Rachels (7) and Gillon (8) have both argued that there can be no necessary moral difference between killing and letting die, but as Gillon argues, it does not follow that they are necessarily morally equivalent. There may, therefore, still exist a moral difference between switching off a respirator and discontinuing dialysis. In what could this difference lie?

I suggest there is a clear difference in our emotional reaction to the two steps that derives from the different emotional importance of the organs whose function is being artificially replaced. Breathing is a very visible process, which has throughout history and literature been equated with life itself. Only since the (recent) availability of artificial respiration has it been possible to divorce the two, and there remains resistance to the acceptance of criteria for death other than inability to breathe. In contrast, the function of the kidneys, though no less vital, is largely unnoticed, and indeed renal failure can develop without any symptoms whatsoever. We do not accord renal function the same status in our conception of the human organism as we do breathing. In addition, whereas the result of cessation of breathing is almost immediate death (in that the other organs of the body will also fail very quickly), death as a result of renal failure, though no less inevitable, may take days. Now whereas the different timescales cannot, I think, have any moral relevance, it is perhaps open to debate as to whether or not the emotional import placed on breathing makes discontinuing artificial respiration a more significant act in moral terms than discontinuing dialysis.

One practical difference between the two forms of therapy that has potential moral importance is that patients on respirators almost invariably have considerably reduced autonomy, in that in all but exceptional circumstances they are either unconscious because of their underlying disease, or are effectively sedated, with or without paralysis, in order to allow them to tolerate the respirator. By contrast renal failure and dialysis do not necessarily lead to any significant reduction in autonomy, although in some cases they may coexist with disease of other organs, leading to reduced autonomy.

In the case of a patient with unimpaired autonomy on regular dialysis, it would seem uncontroversial that the wishes of the patient regarding the continuation of treatment should remain paramount, and it would seem therefore to be incumbent upon the patient's doctor to ascertain what those wishes are. Both the moral and legal right of patients to refuse life-prolonging treatment is now established (4), though the doctor should seek to explore the reasons for refusing treatment and correct any misunderstandings that the patient may have.

When a patient wishes to continue to receive dialysis treatment it is at first sight difficult to imagine any situation in which it might be considered ethically sound to refuse that treatment. The only possible exceptions to the *prima facie* obligation

to respect competent patients' requests for life-prolonging treatment allowed in the Appleton Consensus (4) are that doctors are not obliged to provide physiologically futile treatment, and that 'scarcity of resources may sometimes require overriding a patient's request for a life-prolonging treatment'. (The other two exceptions, namely treatment involving loss of function or mutilation disproportionate to benefit, and treatment to which the doctor has a conscientious objection, are not relevant in this instance.)

Dialysis, if properly conducted, is never physiologically futile, in that it will correct uraemia and fluid overload. However, if it is seen as part of the overall treatment of the patient, and that overall treatment of the patient (for example including chemotherapy for advanced malignancy) is considered futile, then it might be argued that dialysis is one part of an overall futile treatment strategy and so the doctor is not obliged to provide it.

However, the crucial question here is surely the effect of the dialysis itself, rather than that of the overall treatment. If the effect will be to give a few more days of life of reasonable quality (good enough that the patient should want to go on living), then it is not futile treatment, and there is no reason to override the patient's views. Moreover, in these circumstances the continuation of regular dialysis sessions may be of psychological comfort to the patient, and for a doctor to discontinue dialysis against the patient's expressed wishes would appear to be cruel.

The issue of scarcity of resources is clearly very relevant to discontinuation of dialysis. In Britain the facilities provided for the treatment of end-stage renal failure are inadequate, in the sense that there are many patients who die of renal failure who could be kept alive on dialysis (9,10). While some of these cases are explained by failure of referral of patients to renal units for consideration of dialysis, it is undoubtedly true that many units are working to capacity, and the discontinuation of dialysis for one patient (whether due to death or successful transplantation) means the capacity to take on another.

This being the case, the doctor in charge of a renal unit has a responsibility (in addition to clamouring loudly for more resources for the treatment of end-stage renal failure) not only to the individual patients already on the dialysis programme, but also to the potential and future patients who will present to the renal unit with renal failure requiring dialysis in the near future. Clearly the doctor's duty to continue to provide treatment to an existing patient (especially one for whom she has cared for years) is greater, other things being equal, than the duty to provide treatment to any potential patients.

However, potential patients become actual patients, and there may be circumstances in which other things are not equal, namely the existing patient may be elderly and disabled and a burden on her carers (both professional and non-professional),

whereas the potential new patient may be young, otherwise fit, economically active and with a family to support. Further, considerations of justice might suggest that given the scarcity of dialysis it might be allocated on the basis of a fixed number of years per person. All of these considerations suggest that there may be circumstances in which it would be ethical for a doctor to discontinue dialysis for a competent patient even against that patient's autonomously expressed wishes.

The fact that we react with horror to the idea of having to tell a mentally competent patient who wishes to continue to receive dialysis that she can no longer do so is good argument, I think, for there being little, if any, moral difference in these circumstances between killing and letting die. The only circumstances in which it could even begin to be acceptable would be if at the outset of chronic dialysis treatment the limited duration of that treatment was explained to the patient. This would raise a number of practical and ethical difficulties. For example, if after a patient's allotted ten years (say) of dialysis there were spare dialysis spaces available would the patient be allowed to continue to receive dialysis? And if so, how long for – until another new patient needed the facility? In which case the situation would again arise of having to tell the patient at short notice that dialysis was to be stopped.

In clinical practice the question of discontinuation of dialysis for a competent, fully autonomous patient rarely arises. What is far more common is that patients who are on the dialysis programme, who once were competent, become increasingly ill and lose both their quality of life and their competence. It is then that the question of discontinuation of treatment arises. For example, a chronic dialysis patient who is a bilateral amputee and has also lost fingers through ischaemia develops a septicaemia and is unconscious. Should antibiotics and full supportive treatment be given, or should all treatment, including dialysis, be withdrawn? A chronic dialysis patient develops aphasia and a dense hemiplegia due to a cerebrovascular accident. Should rehabilitation with speech and physiotherapy be attempted, or should dialysis be stopped?

In these circumstances the crucial piece of advice offered by the Appleton Consensus guidelines is that 'the doctor, in consultation with the family, if available, and other direct care-givers, should identify the plan of care that would most generally be thought to advance most such patients' interests', and this should be implemented. Of course the question 'what plan of treatment will advance this patient's interests?' may be no easier to answer in practical terms than the question: 'Is it ethical to discontinue dialysis?', and to a certain extent may be seen as an alternative way of asking the same thing. It should be noted that this does not consider the issue, discussed above, of scarcity of resources, and the effect this may have on the doctor's responsibilities.

The Appleton Consensus also states that ‘the doctor also has the obligation to ensure insofar as possible that the patient’s own values and preferences in regard to the current situation are ascertained’, and I think this provides a clue as to how the issue might best be approached. In the circumstances discussed this is clearly meant to be a retrospective ascertainment, presumably by means of interviewing relatives or friends about any wishes the patients may previously have expressed. For patients with chronic renal failure on dialysis programmes, however, the circumstances are such that it might be made prospective. The reasons for this are threefold.

Firstly, patients on dialysis are already in more or less continuous contact with the medical profession. Secondly, the increased morbidity and mortality of patients on dialysis means that they are very much more likely to be in the sort of situation described above in which these questions arise. Finally, when they do fall ill and are in those circumstances, they will almost certainly still be under the care of the doctor who had the responsibility for supervising the dialysis treatment.

This being the case, it would seem to be not only advisable, but ethically required of any doctor looking after patients on chronic dialysis, that she discuss with her patients, whilst they are still relatively well and in particular whilst they are still competent, the circumstances in which they might wish to discontinue dialysis.

This suggestion has been made previously (3). Discussing treatment cessation issues with patients, though uncomfortable for doctors, is not unacceptable to patients (11). In response to a questionnaire on treatment cessation issues 68 per cent of a Canadian dialysis population said they could imagine circumstances in which they would choose to stop treatment. These ranged from being in an irreversible coma to having difficulties with transport to and from the dialysis centre. The questionnaire is reported to have stimulated further discussion between patients and staff.

Discussions of this nature between patient and doctor could form the basis of an advance directive about medical treatment, more usually spoken of in the context of cardiopulmonary resuscitation and ‘do not resuscitate’ (DNR) orders. The recent Patient Self Determination Act in the United States makes it mandatory for hospitals with provider agreements with Medicare and Medicaid to advise patients on admission of their right to execute advance directives. The main argument put forward for this is that advance directives enhance patients’ autonomy, by extending competent patients’ autonomy to the stage at which they have become incompetent.

One criticism of advance directives is equally applicable to my suggestion that patients and doctors should discuss in advance the situations in which dialysis might be discontinued. This is the

argument that competent people are no better placed to make decisions about their future incompetent selves than anyone else, or more particularly than surrogate decision-makers (for example relatives) or their doctors. In its strongest form this argument holds that the one-time competent and future incompetent individuals are in fact not the same person, so that the former has no right to determine what may happen to the latter (12). I do not think that this is consistent with most widely held (by lay people) beliefs about the nature of personhood. However, it may be that an individual patient will acknowledge this, (possibly not explicitly) by saying in her discussions with her doctor that she does not think that she (now) can decide what should happen to her at a later date when she might be incompetent. This in effect is the analysis that would underly a patient naming another as a surrogate decision-maker, but it does not undermine the general principle that such discussions should be held.

There is no doubt, however, that discussions would need to be undertaken with sensitivity and in an unhurried manner. In this country the shortage of renal doctors means that the overall number of patients on chronic dialysis programmes for whom each is responsible is over one hundred, and if patients with functioning transplants are included, the figure is twice this (13). (The figure for the rest of Europe and the USA would be 30 and 6, respectively). In addition, at present, each renal doctor will be responsible for over 50 new patients being admitted onto the programme per year. In these circumstances it is difficult to envisage renal doctors having the time to spend with each patient to explore these issues with the tact and delicacy necessary. Correct ethical behaviour may thus be another casualty of overstretched resources.

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