Support after discontinuation of dialysis—medical and ethical considerations

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Medical considerations

Treatment with the ‘artificial kidney’ permits patients with terminal renal failure to survive for many years, the age of the patient at the commencement of dialysis being an important prognostic factor. According to statistics relating to current practice, patients aged less than 65 at the commencement of dialysis have a 65% probability of surviving more than 5 years [1]. Furthermore data from our own centre indicates that patients starting dialysis at the age of 80 or older have a 50% chance of surviving for 36 months and spend only 10% of this time in hospital [2]. On the other hand there are reports from North America that in patients who are older than 70 the leading cause of death (22%) is discontinuation of dialysis—frequently at the request of the patient and the next of kin [3,4].

Not surprisingly sparse data is available on the symptoms patients experience after withdrawing from dialysis treatment. A recent, partially prospective, study of 18 patients who had chosen to discontinue chronic dialysis indicated that the majority had a ‘good death’, but, and this is disconcerting, eight patients suffered constant pain in their remaining days [3]. The average time from discontinuation to death was 9.6 days, with a range of 2–34 days. It is particularly important to note that, as the authors point out, six patients (33%) were still alive 2 weeks after withdrawal from dialysis. On the basis of this data and from experience of two of our own patients, perhaps exemplary cases, the question is raised as to how the basic needs of the patient (comfort, cleanliness, pain relief, human care, and nourishment) should be provided following discontinuation of dialysis for medical reasons (stroke, myocardial infarction, cerebral events, etc.) when such therapy is no longer clinically indicated.

As a result of the increasing survival of elderly patients, there is an increase in the number of such patients being offered dialysis, and this implies that it will become more common for dialysis to be withdrawn, as medical complications such as those indicated previously will occur more frequently in this group. In this situation it should not be difficult to provide basic nursing care with respect to comfort, pain relief, and nutrition but control of fluid intake could prove difficult, as the majority of dialysis patients are essentially anuric and, in addition, many complain of increased thirst. This then raises the important question as to whether discontinuation of dialysis should automatically exclude the possibility of mechanical elimination of fluid. Should there not be a distinction between blood purification (dialysis) and the removal of water (ultrafiltration) when death does not occur quickly following a decision to stop dialysis? Omission of dialysis guarantees that death from uraemia will ensue and ultrafiltration will not alter the course of uraemia, although it will allow for the provision of nutrition, especially fluid. It is possible that the restriction of food and fluid contributes to pain and discomfort after dialysis withdrawal. The requirement for ultrafiltration will depend entirely on clinical circumstances, if the patient does not develop signs of fluid overload then fluid removal will not be required. There is thus a need for frequent clinical examination of the patient as dietary restrictions are removed, but all routine blood testing should be stopped.

Case 1

A 79-year-old patient with advanced renal failure and diabetes mellitus appeared much older than his years, probably due to the coincidental advanced Parkinson’s disease, which was difficult to control. In view of the progressive decline in renal function and with the patient’s consent a shunt was inserted and dialysis commenced in the hope that control of uraemia would result in a general improvement in his clinical status. A few days after his 80th birthday his condition deteriorated and when questioned about continuing dialysis he did not give a clear answer. His next of kin favoured discontinuation. In view of the overall situation and the fact that even intensified dialysis had not...
resulted in improvement, regular dialysis was discontinued but fluid intake and nutrition was maintained. Ultrafiltration, considered reasonable by the next of kin, was undertaken (3 × weekly for 90 min) and death followed about 2 weeks after withdrawal of dialysis.

Case 2

A 76-year-old patient receiving chronic dialysis was admitted to hospital with progressive gangrene of both feet. In spite of intensive vascular surgery both legs required amputation, following which persistent pain required continuous morphine administration. As the patient could no longer take oral food a nasogastric tube was passed and subsequently a PEG was inserted. The patient was unable to express herself with respect to continuation of dialysis, the next of kin favoured discontinuation. It was agreed that dialysis be withdrawn but that regular ultrafiltration be continued to permit nutrition and fluid balance to be maintained. In less than 2 weeks the patient died from uraemia.

Ethical considerations

Considerations on the discontinuation of dialysis

The ethical distinction between ‘refusing life-extending medical treatment’ and refusal to ‘satisfy basic needs’. The refusal of dialysis therapy results in death but does not cause it. There is thus, when considering the discontinuation of treatment in dialysis patients, a fundamental ethical distinction between satisfying a person’s basic needs and medical treatment to combat disease [5].

One of the inalienable human rights is the right to life until death. As a very minimum the right to have one’s basic needs satisfied is a right that is granted by life itself. These basic needs are those which a newborn is unable to provide for himself or herself such as nourishment, cleanliness, bedding, relief from pain, and above all human care. In patient care the provision of fluid and nutrition is not given with the intention of treating disease, as assumed by the American Academy of Neurology [6], but is given to satisfy basic needs. These cannot be withheld from any human [7]. The withholding of food from a patient with the intention of inducing death is a conscious act of killing by inaction. This is most obvious when nutrition is withheld from patients who will not die from their disease in the foreseeable future. The withholding of nourishment is a direct act against life. The obligation to provide for the basic needs does not mean that one has to fight death with all available means. Basic needs exist independent of disease, it is just that the patient may not be in a position to provide them him/herself as a result of disease. In contrast, medical therapy is directed at treating disease and as such is only sensible if such treatment offers a satisfactory quality of life to the patient. A justifiable refusal of treatment in terminal illness does not itself reflect on the value of the life of the person. It is instead simply an acceptance of the fact that a particular disease is irreversible and beyond present medical expertise, and thus life is given over to its fate. A refusal to further treat terminal disease allows inevitable progression to occur. However, it does not cause death as would be the case if nutrition and fluid were withheld. Such a refusal arises from acceptance of the fact that the clinician has exhausted all therapeutic options of benefit to the patient and that death can no longer be ‘manipulated’ but should rather be accepted. The goal of medical treatment is not to fight against death but to provide for life that is acceptable to the patient and not just a technical extension of the process of dying.

Consequences of discontinuation of dialysis

Dialysis is a mechanical (artificial) replacement of a vital organ system, the ‘mechanical’ interruption of a ‘natural’ process of dying. The body is no longer able to accomplish the functions that are necessary to maintain life. In such circumstances the withholding of dialysis does not cause death but rather permits it. A discontinuation of dialysis without the consent of the patient can only be ethically justified when the patient has permanently lost control of their faculties and when the renal failure is accompanied by other severe organ dysfunction (cases 1 and 2) which are progressive and will result in death within a foreseeable period of time. In addition the majority of such patients are, as a result of their illness, either incapable or only partially capable with respect to their ‘legal capacities’. In these conditions a discontinuation of dialysis when consent is lacking or the patient is unable to provide consent is not ethically justifiable on the grounds that such a life is not worth living but rather that the dying process has begun and that it is not possible to stop the process in a manner acceptable to the patient.

Ethical considerations regarding nourishment after discontinuation of dialysis

Withdrawal of dialysis without discontinuing nourishment. Refusal to continue to treat the disease (renal failure) does not mean that nutrition should also be withdrawn, i.e. the discontinuation of the provision of basic needs. This would be an ethically unacceptable act against the life of the terminally ill patient.

In accordance with the above-mentioned ethical considerations, it is necessary to eliminate the argument which claims that when the aim of withdrawal of dialysis is ‘to allow nature to run its course’ then nourishment should also be withdrawn because the same goal (death) will be achieved more quickly. This would negate the basic distinction between satisfying basic needs on the one hand and the refusal to treat the disease on the other, and also the distinction between allowing death and the conscious act of causing death (killing). If a decision and action are ethically assessed only with that objective in mind, the means by which the end is achieved appears to be of secondary ethical importance. The goal of relieving suffering is
identified with the goal of ending life. True help in
dying does not aim to achieve death, but to relieve
suffering, and to allow life to find its own end and not
to be determined by the patient or others. This is
accepted when in terminal illness further medical treat-
ment is declined while at the same time everything is
done to relieve pain to make life bearable for the
patient. This may lead to conflict where theoretically
clearly defined distinctions dissolve into grey areas
where evidence-based distinctions do not exist and
where actions are not primarily derived from the
consequences of the action (death).

Nutrition by expensive mechanical means. In accordance
with the considerations above, it is obligatory that the
basic needs of the patient, including nutrition, be
satisfied until death [8]. The question, however,
remains as to whether this obligation is independent
of the degree of disability and its cause and independent
of the amount of technical effort involved. In patients
with renal failure it is possible to supply nutrition and
fluid naturally or by nasogastric tube, whereas a com-
plicated mechanical process is required to remove
excess fluid to maintain the patient in fluid balance.
This raises the question as to whether in such patients
nutrition and fluid balance is an ethical obligation.

It is not possible to derive supposed ethical demands
directly from ‘natural facts’ (naturalistic fallacy), but
it is reasonable to ask which helpful concrete examples
of ethical perspectives are possible through reference
to natural phenomena. If the satisfying of basic needs
consists in all that required by a newborn, which it is
unable to provide for itself, then one comes to the
sensible distinction between a natural and always obliga-
tory means, and an unnatural and therefore extraordi-
ary and not always obligatory means. Breathing, diges-
tion, excretion, amongst other things, can be
performed by an infant itself. When a person as a
result of some advanced irreversible disease is not able
to breath for himself/herself, then he/she is dying. In this
case it is not obligatory that the failure of this vital
organ function be replaced by an ‘unnatural’ breathing
device. Analogously it is necessary in patients with
failure of digestion to provide external nutrition in an
appropriate form but it is not necessary to provide
intravenous nutrition [9,10].

In patients following withdrawal of dialysis one
could decide to continue to provide nutrition by natural
means and yet death will still ensue. A refusal to
provide nutrition might influence the process of dying
in a relatively short time after dialysis discontinuation.
A refusal to provide fluid quickly leads to death due
to dehydration, i.e. the death is caused by the with-
holding of fluid. Even if the interval between death as
a result of dehydration and death due to uraemia is
not long, it is indisputable that, on the basis of the
distinction between refusal to treat medically a fatal
disease, and to provide basic needs, the physician is
involved in the dying process in a different manner,
and as a consequence the inviolability of killing has at
least been breached. Doubt and questions of conscience
with respect to the inviolability of killing should be
avoided, particularly by medical personnel. To that
extent, from this basic ethical–obligatory perspective,
the provision of fluid and even calories is to be given
priority over their refusal, even if this means that
ultrafiltration will be required [9].

Fluid administration and ultrafiltration in the support
of the dying. Withholding of fluids not only causes
death, but dying from dehydration is, according to our
knowledge, painful, and perhaps even more so for
patients with uraemia. Increased suffering is caused
more than by death from uraemia alone. On the other
hand, death from uraemia is not prolonged if ultrafil-
tration is required. As far as can be determined,
everything is in favour of fluid administration and
ultrafiltration as required to support the dying patient;
it reduces suffering and makes death easier. As such it
is always ethically required. It is therefore not only
obligatory in providing for basic needs, but rather and
perhaps even more, because of the obligation to relieve
suffering and make death easier. There is thus a
differentiation between the refusal to provide dialysis
and the continuation of ultrafiltration, whereby the
latter is not only humane but desirable.

These ethical considerations are valid in that the
inviolability of killing always remains valid, even if the
period of time until death ensures can be fairly accur-
ately predicted. It is not possible to conclude from
approaching death as a result of a terminal illness (e.g.
renal failure and its consequences) that the refusal to
provide further treatment simultaneously represents a
justification to end life. A killing which would end the
dying process quickly and apparently ‘with the least
pain’, and which in addition saves the cost of treatment
which has no apparent benefit for the patient, has no
justification.

In view of the increasing economic pressure on social
and health-care structures it will be necessary not to
succumb to the alternative that if nothing can be done,
then life should be put to a quick and painless end.
Ultimately this is the choice between healing or killing,
and therefore the human life loses its right to legal
protection if it becomes a burden to society [5]. The
medical profession can act against this if it accepts that
the relief of suffering is as inviolable as the responsibility
for healing. The ethical approach proposed here in the
withdrawal of dialysis serves this obligation: to serve
life, and to reduce suffering without taking life.

References
1. Valderrabano F, Berthoux FC, Jones EHP, Mehls O. Report
on management of renal failure in Europe, XXV, 1994. End-
stage renal disease and dialysis report. Nephrol Dial Transplant
1996; 11 [Suppl 1]: 2–21
performing kidney replacement therapy on patients over 80?
Nephrol Dial Transplant 1996; 11: 2412–2413
3. Cohen LM, McCue JD, Germain M, Kjellstrand CM. Dialysis
discontinuation. A ‘good’ death? Arch Intern Med 1995; 155:
42–47


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