Justification for a home-based education programme for kidney patients and their social network prior to initiation of renal replacement therapy

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ABSTRACT

In this article, an ethical analysis of an educational programme on renal replacement therapy options for patients and their social network is presented. The two main spearheads of this approach are: (1) offering an educational programme on all renal replacement therapy options ahead of treatment requirement and (2) a home-based approach involving the family and friends of the patient. Arguments are offered for the ethical justification of this approach by considering the viewpoint of the various stakeholders involved. Finally, reflecting on these ethical considerations, essential conditions for carrying out such a programme are outlined. The goal is to develop an ethically justified and responsible educational programme.

INTRODUCTION

Renal replacement therapy

When an individual faces loss of renal function and requires renal replacement therapy (RRT) they have a number of treatment choices: haemodialysis, peritoneal dialysis, or transplantation with a deceased donor kidney or with a living donor kidney. The main benefit of dialysis is maintenance of life, however, the patients' physical and psychological condition is considerably compromised.[1 2] Morbidity and mortality rates while on current dialysis treatment modalities are higher than when the patient receives a transplant.[3 4] Transplantation therefore offers an alternative. However, there is a worldwide shortage of kidneys from deceased donors available for transplantation. In 2009 in the EuroTransplant zone there were 11 010 patients on the waiting list for a kidney transplant while only 3558 were actually performed, and the median waiting time for deceased donor kidney transplantation was 4.5 years (http://www.eurotransplant.org/). While waiting for a deceased donor kidney transplant (DDKT) patients are treated with haemodialysis or peritoneal dialysis. Living donor kidney transplantation (LDKT) provides an alternative to DDKT and confers sizeable advantages for graft and patient survival.[5 6] With increasing acceptance of LDKT in many countries, there has also been an increase in kidney transplantations that take place prior to commencement of dialysis, so called pre-emptive transplantation. Pre-emptive transplantation offers optimal graft and patient survival when compared to living donor kidney transplant after dialysis.[5 7 8] Furthermore, the lengthy waiting time for a deceased donor as well as the decline in quality of life, comorbidity and access surgery associated with dialysis can be avoided.[4 9] Return to employment is also highest among pre-emptive transplant recipients.[10] Pre-emptive transplantation is economically advantageous for health insurers as it avoids the considerable costs of dialysis. However, some theoretical disadvantages of pre-emptive transplantation have also been highlighted.[8] Concerns reported in the literature include confronting the patient with kidney disease in a period that is often asymptomatic, performing transplantation too early, unnecessary transplantation of patients who might have eventually recovered renal function, and risk of non-adherence in patients who have not experienced the adverse effects of dialysis or the burden of kidney disease in the last stage prior to RRT. However, these concerns, in our view, do not outweigh the benefits of pre-emptive transplantation.

In The Netherlands, 43% of living donor transplants were conducted pre-emptively in 2009.[11] Therefore 57% of patients transplanted with a kidney from a living donor underwent dialysis first. Even taking into account the concerns regarding pre-emptive transplantation, this is an undesirable situation given the important benefits of this treatment. In order to make pre-emptive transplantation a real option it must be included in patient education prior to commencement of RRT.

Patient education

In order to make an informed decision on treatment patients need to be educated on these options prior to initiation of RRT. It is possible to identify a number of medical, individual, social, organisational barriers to fully informed decision making about first form of RRT.[12] Individuals may not be aware of all the treatment options available to them prior to RRT initiation, they may believe that transplantation must be preceded by dialysis or that transplantation is a last resort, and they may have a lack of knowledge or misconceptions about risks and financial consequences of the various RRT options.[12] Patients may also experience emotional barriers such as fears regarding finding a living donor, health risks to the living donor, the impact of donation on relationships and fear of surgery.[13 14] For patients wishing to pursue pre-emptive transplantation, a living donor is usually required (in The Netherlands). Research has shown that living donation is a difficult topic to discuss and patients would appreciate support in this.[15] This is likely to be particularly difficult in an early stage when there is less apparent urgency for transplantation. Organisational barriers that preclude the option of pre-emptive transplantation include failure to discuss transplantation prior to initiation of dialysis and late referral of patients for transplant education and preparation.

In the current situation it is unclear when and how transplant education is given to pretreatment phase patients with end-stage renal disease. Patient education on transplantation is likely to depend on and vary widely according to the nephrology team and centre in which the patient is being treated. In some cases, particularly if there has been no referral to a pretransplant clinic, transplant education may be the responsibility of dialysis nurses and doctors who may, or may not, be sufficiently conversant on transplant issues. Moreover, it is theoretically possible that financial considerations may conflict with offering transplantation as a treatment option for those whose income depends on the treatment of patients on dialysis. Although financial benefit for the transplant centre could also be a factor when patients are transplanted too early. Accordingly, the rate of pre-emptive transplantation is likely to vary between centres and countries in the same way living donor transplant rates vary.

Ethical considerations

In the current analysis we consider the ethical implications from the viewpoint of various stakeholders and outline the ethical prerequisites for carrying out such an intervention. As van Dijk and Hilhorst explain, we must consider the possible impact and harm of introducing a new system as well as considering of the harm involved in the current situation.[16] Our goal is to conduct an ethically responsible educational programme. We will consider the education in light of the ethical values of autonomy (right to self-determination), beneficence (promoting well-being), non-maleficence (doing no harm), and truthfulness and honesty (informed consent).

EARLY INTERVENTION: A NEW PROPOSAL

Given this possible suboptimal situation, we suggest a new approach (that will be tested in a research setting). In the current situation it is likely that the doctor informs the patient of the advantages and disadvantages of RRT options and might encourage them to consider living donor transplant but the task of finding a donor is left to the patient. A number of alternative approaches to patient and family education on living donation have been described. One is the 'Norwegian approach' whereby the doctor discusses potential living donors with the patient and then personally contacts these individuals.[17] The doctor informs the family member or friend of the patient's situation and the possibility of living donor kidney transplantation, and invites potential donors for evaluation. This approach removes the responsibility of discussing living donation from the patient, but does not offer support for the patient and his/her family to communicate about treatment options with one another. Another approach is James Rodrigue's home-based education programme whereby a psychologist gives transplant education to the (pre)dialysis patient and their family and friends in the patient's home.[18] This programme has proved successful in increasing knowledge and willingness to communicate about living donation and in decreasing living donor transplant concerns. Furthermore, the number of enquiries and evaluations of living donors increased.

We propose adapting this 'house call' approach by offering the educational meeting earlier in the clinical course and broadening the scope to include all RRT options (dialysis and transplantation). In our programme, patients will be offered an educational meeting in their own homes (or at another location outside the hospital if desired) conducted by a trained educator (eg, a medical social worker) before initiation of any RRT. Offering education on all RRT options early in the clinical course ensures that all treatment options, including pre-emptive transplantation, are still available to the patient. Moreover this approach enables patients to consider the pros and cons of each RRT option alongside one another (eg, of dialysis, living and deceased transplantation at a later stage). During an initial intake consultation with the educator, the patient will be encouraged to invite their self-chosen social network to attend the subsequent educational meeting so that they too will be better informed. A written invitation can help in this process. During this initial consultation the educator should discuss the extent to which the patient wants to be involved in the group session (eg, to describe their own experiences) and possible confidentiality issues (information the patient prefers not to divulge to the group). The subsequent group educational meeting should focus, in our view, on consideration of the advantages and disadvantages of all the various RRT options (haemodialysis, peritoneal dialysis, DDKT and LDKT) and facilitating communication about these options. A confidential follow-up consultation can be offered to those present if necessary. It is our aim to empower patients and their social network by providing them with the tools to make a well informed decision about RRT in full knowledge of the risks and benefits early enough in the clinical course when all treatment options are still available.

In the proposed programme education on all RRT options will be standardised over the participating dialysis centres and tested in a research setting. In other words, the type of educator, the method of delivery, the content and timing of the education will be protocolised and thus consistent regardless of where or by whom the patient is being treated. Therefore patients will have equal access to the same standard of care, thus increasing fairness of the system and equality in access to information. This is preferred to the current system in which transplant education is unstandardised and widely varying.

Stakeholders' viewpoint

The proposed programme involves a number of stakeholders: the individual with (gradual) loss of kidney function, those in the patient's social network who are invited to the educational meeting, and the healthcare provider (HCP) who will give the education and/or is involved in the patient's care.

The patient

Previous research has shown that the majority of patients with end-stage renal disease prefer living donor to deceased donor transplantation[14] and are willing to accept the offer of a living donor kidney.[13–15] However, they fear the possible risks and burden to the donor, as well as negative reactions and find it difficult to ask or discuss living donation directly.[14 15] Patients feel that a kidney should be offered completely voluntarily, which prevents them broaching the subject so as not to put pressure on friends and family.[15] These studies emphasise the wish and need for assistance or support in communicating with family and friends regarding RRT and in particular living donation. Our programme intends to meet this need.

The focus of the suggested programme is on the psychosocial perspective.[19] While nurses and doctors may discuss primarily the medical advantages of certain treatments above others and the physical implications, educators who visit the home will discuss the social, psychological and functional implications. They can help evaluate how each treatment might fit into their lives and will impact upon their quality of life. The programme's aim is one of patient empowerment, giving patients and their network the tools to make their own well considered decisions. We should note that this psychosocial consultation is additional to other efforts to inform the patient, for example, on the technical aspects of dialysis. The choice between available RRT options is a decision made based on medical and other considerations and is ultimately made together with the nephrologist. Therefore, the focus of the home-based programme is on knowledge and communication regarding RRT options. The success of the programme will not be assessed on choice of RRT but rather on the tools necessary to make a well informed decision. We trust that our proposed patient-centred, home-based education provides a setting that is personal, informal and safe for the patient. This implies that the meeting can also take place in another convenient setting, if preferred by the patient, such as a community centre.

The proposed programme ensures respect for autonomy, that is, making sure that individual patients can make their own informed decision regarding their treatment rather than this being determined for them by others (paternalism). In order to do so they need to be aware of all the treatment options at a moment in time when all options are still available to them. Withholding information on a certain treatment (intentionally or not) or informing the patient too late in time, making an option redundant, would be unacceptable. Our programme in the early stages of the clinical course will ensure that the patient is fully informed in a timely fashion. In addition, patient participation in the educational meeting is completely voluntary and should be based on sound information about the programme. The choice of those who do not wish to participate in the offered meeting should be recognised and respected. Moreover, the patients are free to choose who they wish to invite to attend.

Another basic principle of medical ethics is non-maleficence. To what extent might this education cause harm to the patient? One important objection to patient education in the pretreatment phase is that the patient is confronted with his/her illness at a much earlier point in the clinical course and often when the disease is asymptomatic. This news might be shocking or unpleasant, and one may prefer to avoid this. This, however, should be balanced against the situation that one is not told about all the options and their consequences. Withholding information and denying a patient an option constitutes a serious harm and also wrongs a patient in that it does not respect the patient's own judgement. It is, of course, up to a patient to decide whether or not to participate in the education programme and become informed.

The patient's social network

Following Rodrigue, the proposed programme incorporates a multisystems approach. The patient is not seen as an isolated entity but as an individual imbedded in multiple social systems such as immediate and extended family, friends, colleagues, social groups, organisations or societies and the larger community. Those closest to the patient are likely (but not necessarily) to be the best informed about kidney disease, its impact and treatment. These individuals may accompany the patient to the hospital and educational meetings. Others in the social environment are less likely to be well informed, and their knowledge will depend on their own level of curiosity as well as how much the patient chooses to share with them. In the proposed programme we aim to reach a larger target audience than is currently possible in the hospital setting. It is possible that there are individuals who have questions but are afraid to ask OR. This can develop into a stalemate situation whereby the patient will only accept a spontaneous offer but family and friends are unaware of the need, possibilities or consequences of treatment (particularly in an early stage of the clinical course). Experience has also taught us that living donors often wished they had known of the possibility to donate earlier in order to spare their relative or friend the loss in quality of life and reduced health condition resulting from dialysis. The house call approach offers the chance for family and friends to learn about the situation of the patient, air their own needs and concerns, and discuss possible misconceptions or misunderstandings.

One ethical consideration is whether the 'house call' approach is a suitable and acceptable method of educating the family and friends of patients? Is it justified to invite individuals for an educational meeting who otherwise might not receive any education on this issue and would have been 'left in peace'? When a relative or friend is on dialysis, living kidney donation may be a less pressing issue. Given the autonomy of the individuals invited, attendance and participation should of course be voluntary. Individuals have a 'right not to know' and should be able to decline the offered programme. But more importantly, we believe, the decision as to whether they wish to receive this information should be left to the individual and not be withheld by professionals for fear of interference. Another consideration is the possibility that offering group education to family and friends will uncover reluctance or refusal to consider living kidney donation. This could have negative consequences for the relationship between the patient and the individual. However, the offer of education does not cause or alter the attitude of the patient's relative or friend.

A second ethical question is to what extent our programme would influence (increase or decrease) the perceived pressure to donate? A basic tenet of living kidney donation and donor screening is that donation should be voluntary; therefore undue pressure or coercion of any kind to donate should be absent. Indeed, the absence of pressure or coercion in living kidney donation is stipulated in the national Dutch donor screening guidelines and in many international guidelines for evaluation of living donors.[20 21] Also, according to Dutch law living kidney donation is forbidden if the individual is under pressure to donate or has not been informed of the risks (Organ Donation Act 1996, article 3.2[22]). We should, however, be aware that not all pressure can be avoided; pressure to consider living donation is implicit in the situation where a relative or friend has renal failure. An internal sense of duty to consider donation however does not necessarily compromise the voluntariness of a donation, however stressful the circumstances might be.[23] Yet education meetings make the option of living kidney donation explicit, which may generate an increased feeling of pressure. The invitation (alone) could be construed as an attempt to persuade the individual to donate a kidney. Misunderstanding about the goal of the meeting and the intentions behind the programme should be addressed in a written informational invitation form. This information can help allay feelings of external pressure to donate. Furthermore, any form of pressure that is inherent in the situation cannot be attributed to the informant. We would therefore argue that under the condition that the goal is not donor recruitment, this type of educational programme is not likely to increase the pressure felt to donate but may offer a release of any felt pressure and anxiety regarding this difficult-to-broach topic.

Third, can the content of the education be considered as coercive? Unbalanced education in which only the benefits of living kidney transplantation and the disadvantages of other forms of treatment are emphasised could be construed as coercive and unethical. Hilhorst *et al* have described the pitfalls of (mis)representing information. Therefore another requirement of the educational programme is that the information given is non-directive, highlighting the advantages and disadvantages of all treatment options. The specific situation of the patient should also be taken into consideration. For example, an advantage of peritoneal dialysis is that it offers greater independence from the hospital including the possibility to work. In this way we appreciate that all information given is person relative and understood within the specific context, beliefs and experiences of that person.[19] Educators should be truthful and open regarding benefits of transplantation for the patient over dialysis, living over deceased donor transplant, and pre-emptive over transplantation after dialysis without overlooking the disadvantages.

Finally, there is an issue of social dynamics. The educator must be aware of the role division within the social network and the possibility that others, for example, within the family, may try to manoeuvre one individual to donate. This can be a discrete process in which an unspoken consensus is reached within the group as to who should donate. This of course can always happen in living donation, regardless of the education provided. The educator should moderate the discussion and be sensitive to the needs and perspective of each individual whether patient or invited guest. The beliefs, concerns and commitments of family and friends should be respected. This however does not necessarily mean that they cannot be reflected upon and challenged. Misconceptions, for example, regarding the risks for the donor, can be dispelled during the educational meeting. Therefore we feel the open discourse offered by these meetings is more likely to limit undue pressure than to increase it.

The healthcare provider

A number of difficult questions are raised by this project such as whose responsibility is it to inform family and friends of the patient about treatment options and living donation, and who is best able to do this? Is it the responsibility of the patients and are they able to do so? To what extent is it the responsibility of the HCP? Is 'interference' in such an early stage justified? Hilhorst and colleagues have argued that intervention is justified in the context of truthful and person-relative counselling. HCP have a duty to provide all relevant information on treatment options, to ensure understanding of this information and to correct misinterpretations.[19] This would suggest that HCP are obliged not to withhold any information or treatment that may be beneficial. To do so would be unethical and indeed it has been argued that it would be unjust if some patients were disadvantaged.[19] We do not argue that it is the responsibility of HCP to find a donor for the patient; however we do believe that it is the responsibility of the HCP to remove barriers for living donation, and to provide timely and unbiased information to the patient and their self-defined network so as to give them the tools to make a well informed choice in a phase when all options are still open to them.

Essential criteria

Based on this analysis of the ethical feasibility of the proposed project, we outline in box 1 a number of criteria that should be fulfilled in order to develop and conduct an ethically responsible home-based group educational programme in the pretreatment phase of renal disease.

Box 1 Essential criteria for a home-based group education programme on RRT in the pre-treatment phase

- The patient and those they invite have the (moral and legal) right to decline participation in the education programme.
- The patient decides whom to invite to the meeting.
- The patient and those they invite have the right to withdraw at any point.
- The aim of the project is not to persuade participants to become a living donor, but to support autonomous decision making in an early stage and benefit patients and their network by removing prevailing obstacles and unfairness in the current system.
- A written invitation should clearly explain the aims and procedures of the education.
- The meeting should take place in the home of the patient or at another preferred location outside the hospital, if desired.
- The information given should be non-directive and truthful, presenting advantages and disadvantages of each treatment option (namely haemodialysis, peritoneal dialysis, deceased donor kidney transplant and Living donor kidney transplantation).
- The educator should consider the medical perspective and also the social and psychological implications of each treatment option.
- The educator should respect the perspective of all those present at the meeting whether patient or guest.
- The educator pays attention to the role division/hierarchy of those present and to the possibility of coercion and undue pressure.
- All consultations with patient and their social network, including follow-up consultations with any potential donors, should be conducted confidentially. This also includes what information is given to the family and friends during the educational session. This should be discussed with the patient beforehand.

CONCLUSIONS

Based on the above analysis we conclude that the proposed educational intervention is ethically justified. In the current system the information the patient receives regarding first form of RRT depends on a variety of individual, social and organisational factors. Information on transplantation given too late can preclude the option of pre-emptive transplantation and the associated patient and graft survival benefits. We conclude that the 'interference in people's lives' is justified, if not obligatory as proposed in our programme, under the conditions described (box 1). We consider the proposed programme a patient-empowerment approach, aiming to support autonomous decision making. The patient and those in their social network have the right to non-directive, truthful and timely information given in a way that takes into account personal and contextual characteristics. The HCP in turn has a responsibility to provide this service.

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