Living-donor partial liver transplantation: the question of financing

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The first successful transplantation of a liver lobe from a living donor to her son was performed in 1989. The procedure has been carried out routinely in Asia since the 1990s, and it has also become more common in the US since 1998. In Switzerland, about 20 operations of this kind have been performed at the transplantation centres in Geneva and Zurich since 1999. Usually, the larger of the two lobes (60% of the liver) is transplanted. Within a few months, both parts are restored to the normal size through regeneration. Current empirical data indicate that the morbidity rate (incidence of complications) in donors is non-negligible, although it varies from one country to another, and there have even been individual cases of death. Most donors are family members.

Living liver donation is an expensive treatment, with costs amounting to CHF 160,000 per transplantation. In Switzerland, it is currently financed by the cantons and not by the health insurers. The decision not to include this procedure on the list of reimbursable items was defended on ethical grounds. The main ethical issues concern the risks involved for donors and the potential for moral pressure, which may arise within family relationships as a result of the urgent need for transplantation. The topic of living donation was considered by the NEK-CNE in connection with the current parliamentary deliberations on the Transplantation Law drafted by the federal government.

The question addressed to the NEK-CNE by the Federal Office for Social Security (BSV) and the Federal Commission on Fundamental Principles of Health Insurance (EGK) was whether the particular characteristics of living liver donation give rise to ethical reasons why the procedure should not be included on the social health insurers’ list of reimbursable items.

1 Considerations

In view of the risks to the health of partial liver donors and the potential for pressure, society has an obligation to protect such donors. This could even involve protecting donors from themselves, since consent to donate could be prompted by an excessive, self-sacrificing sense of responsibility for someone close to the donor, with personal risks being accepted without due reflection. The possibility of a life-threatening disease being successfully treated with the aid of an organ donated by a relative creates a situation in which the patient is dependent on the relatives who are potential donors.

The latter are vulnerable to the extent that they often see themselves as “having no alternative” but to consent, for moral reasons; their refusal would directly endanger the patient. However, the protection afforded to potential donors cannot consist in a denial of their autonomy, i.e. preventing them from deciding for themselves whether or not to donate. Ultimately, each individual is responsible for his or her own life – responsibility cannot be delegated. Accordingly, only the individual concerned can decide whether or not he or she is prepared to consent to living donation, although the decision should be taken on the basis of the fullest possible explanation of the implications and consequences. The protection of donors concerns not only health-related aspects but also their moral integrity.
It would therefore be preferable to establish a system that helps the individuals concerned to make reliable, authentic and considered decisions, taking account of the risks and consequences. Statistically speaking, the risks of liver donation are higher than those associated with the donation of other tissues and organs, such as bone marrow or a kidney. However, it is not possible to express the highest ethically justifiable level of risk in terms of a general formula. Decision-making processes should be designed in such a way as to enable the risks to be responsibly evaluated in individual cases and considered from various perspectives.

The benefits for the recipient and the risks for the donor are not comparable or commensurable. For example, it is not clear how the additional years of life gained can be offset against the risks incurred by donors. These are two quite different things. A subjective evaluation needs to be made from the donor's viewpoint. Benefits might also include, for example, the significance of the donation for the donor in the context of emotional relationships and the donor's conception of the good life.

An important, indeed indispensable, condition for potential donors’ decision-making process is that it should be voluntary, i.e. free of coercion or attempts to exert pressure. Organ donation must not be the subject of commercial dealings; this is an unequivocal requirement of the draft Transplantation Law.

2 Opinion

1. There are strong ethical arguments in favour of including living liver donation on the social health insurers’ list of reimbursable items.

2. For living liver donation to be conducted responsibly, supporting measures need to be offered which help those concerned – primarily the donors and recipients – to arrive at a reliable, authentic and considered decision.

3. The costs involved in the preparation, treatment and appropriate aftercare of donors – including treatment of any late effects of organ donation – should be borne by the recipient’s health insurer.

3 Statement of reasons

The problem is not resolved by the insurers’ refusal to finance living liver donation since the operation is not thereby prevented, but the associated costs would be privatized. The families who through donation already make an exceptional contribution would feel obliged for the same moral reasons to accept the financial consequences. Moreover, the operation could not be contemplated by poorer families.

For both reasons, the non-financing option would be open to the charge of injustice. That are voluntarily accepted by donors in a spirit of charity cannot be adduced as a reason for relieving oneself of the costs. In addition, there are ethical reasons why the assessment of whether diseases deserve to be treated should not be based on the different levels of costs involved. The fact that the procedure is expensive should be a secondary factor in the decision on reimbursability. The costs of other expensive treatments are also borne by health insurers.

This Opinion was not based on considerations relating to the allocation of scarce resources. The NEK-CNE is aware that it is not feasible to finance everything that is medically possible. However, in order to discuss the question of allocation, other expensive treatments would also need to be systematically reviewed. The criteria for decisions of this kind must be transparent. In addition to costs, consideration should also be given to urgency and the success of treatment in terms of gains in quality of life.
The NEK-CNE has formulated a number of criteria for accompanying measures. The central concern is to ensure that donors are fully informed about medical and psychosocial aspects before they give their consent, and that comprehensive medical, nursing and psychosocial care is provided in the decision-making process prior to and also during and after removal of the organ. Aftercare should be available for the rest of the donor’s life, and any costs arising as a result should be borne by the insurer of the recipient, on whose account the entire procedure is of course undertaken. If these measures can be implemented in the form of an interim solution before the Transplantation Law enters into force, there are, in the view of the NEK-CNE, no ethical reasons why the operation should not be included on the list of reimbursable items.

Conversely, there are strong ethical arguments in favour of granting the operation reimbursable status. Compared with the situation for living kidney donation, the failure to finance living liver donation gives rise to unacceptable discrimination. Whereas a therapeutic alternative exists to living kidney donation (dialysis), there is no such alternative to living liver donation. In addition, the liver is regenerative. Transplantation of a living donor liver lobe can be life-saving. There are not sufficient organs from braindead donors to enable everyone who requires a transplant to receive such treatment in good time. Equally, the protection of donors – which is not directly essential to the success of treatment in the recipient – could be more readily assured if the procedure were recognized by the health insurers.