Transpl Int (2004) 17: 449–452
DOI 10.1007/s00147-004-0744-1

ORIGINAL ARTICLE

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Written information for potential living kidney donors

Received: 13 August 2003
Revised: 1 December 2003
Accepted: 21 April 2004

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Abstract To meet the constantly growing demand for organs for transplantation the use of living related and unrelated donors continues to increase. Transplant units with a living-donor programme often provide written information to their potential kidney donors. We saw a need to assess the contents of these brochures. Written information for potential live kidney donors was requested from different Transplant units throughout the world. We obtained and analysed 16 different brochures from 14 countries. The general approach ranged from persuasive to almost deterring. Sixteen main themes were identified in the information material. Eight of those were considered paramount, namely voluntarism, medical suitability, short-term donor risks, long-term donor risks, risk of graft loss, outcome with and without a living donor, postoperative course, and financial conditions. Five brochures covered *all* these crucial matters. When mentioned, examples and interpretations of donor risks were very dissimilar. Furthermore, the conditions for donation were obviously very different in the various countries. This review points at essential issues to be included in the written information for living kidney donors. All transplant units with a living-donor programme should provide such information, thus enabling the potential donor to make a thorough decision.

Keywords Consent · Decision making · Living kidney donor · Written information

Introduction

To meet the constantly growing demand for organs for transplantation the use of living related and unrelated donors continues to increase. Solid-organ donation by living donors is a remarkable activity where major abdominal surgery is carried out on healthy volunteering individuals. To justify the use of living donors for kidney transplantation these essential conditions have been outlined: (1) the risk to the donor must be low, (2) the decision to donate must be completely voluntary, (3) the donor must be fully informed and (4) the outcome must have a good chance of being successful [1].

When one of two kidneys is donated, the effect on the average donor's health is certainly limited in the short term and in the long term, but the procedure is not without risk [2, 3, 4, 5, 6, 7, 8]. To be able to make a voluntary decision a person's autonomy must be respected. Beauchamps and Childress have described two essential settings for autonomy, namely independence from controlling influences, "liberty", and capacity for intentional action, "agency" [9]. Another prerequisite is that adequate information is provided. Otherwise, the potential donor has no basis for giving informed consent. Appelbaum and Grisso have described four principles for being competent to give a valid consent. They are: communicating a choice, understanding relevant information, appreciating the current situation and its consequences and manipulating information rationally [10]. When competence to consent is being discussed it is not often perceived that people make decisions based on affective as well as cognitive data [11]. It is important to acknowledge the influence of emotions in the decision-making process.

How the information is ascertained in dialogue with the individual potential donor cannot be assessed. Many transplant units with a living-donor programme, however, offer written information as well. The present study explores themes included in such information brochures.

Methods

Written information for potential live kidney donors was requested from transplant units in several countries throughout the world. Attempts were made to retrieve such material from most countries where living kidney donation is performed. Inquiries were made by letter, e-mail and/or personal contact with transplant units in 22 countries. We obtained information material from fourteen of those: Australia, Belgium, Canada, Denmark, Germany, Italy, the Netherlands, Norway, Sweden, Switzerland, Turkey, Poland, the United Kingdom and the United States of America. It was not possible to obtain any material from France (four centres), Greece, South Africa, Egypt, Mexico or India. Transplant units in two countries (Finland and Brazil) provided material that could not be defined as written information for potential kidney donors. For a better coverage of the USA, we included centres from three states. A Flemish and a French language brochure represented Belgium. The Swiss centre and the German centre, used the same brochure in the German language; thus, we assessed 16 brochures.

In two cases, the donor information was included in the general information about renal transplantation also intended for the recipient—otherwise it was a separate print. The Turkish text was translated into English by two Turkish medical students and the Polish text into Swedish by a Swedish nephrologist of Polish origin. The authors translated the Danish, Dutch, Flemish, French, German, Italian and Norwegian texts. We assume that the brochures we were given are the ones used and that each one reflects the official attitude towards living-kidney donation. Forms used for legal purposes were not assessed. Additional material that was available for potential donors and published by other organisations, such as kidney patients' associations, or via the Internet, was not taken into account.

Sixteen themes were identified and each text classified according to these. Furthermore, the design of the presentations was recorded.

Results

Table 1 shows the most frequent themes and how many of the 16 brochures covered them. We saw eight topics as paramount—not to be overlooked. Those were: medical limitations, voluntarism, short-term donor risks, long-term donor risks, advantages for the recipient, the risk of graft loss, postoperative course (notably pain) and financial conditions. Five brochures covered all those crucial matters. At the other extreme, one mentioned only two.

Motives for donation were always dealt with, all but one text stressing that the action be voluntary, without coercion and with a right to withdraw consent. The exception only brought up positive feelings in general.

Two texts denied any short-term risks and four denied long-term risks. These were not counted in Table 1 as giving information on the subject. The most often mentioned specified short-term risks were wound infection ($n=11$), haemorrhage ($n=9$), thromboembolism ($n=8$), pneumonia ($n=5$), and urinary tract infections ($n=5$). The possibility of donor death was pointed out in nine booklets.

Chronic pain was the most frequently acknowledged serious long-term complication ($n=6$). Hypertension was discussed in eight brochures, most often recognised as a true risk but with little or no significance. In three cases the risk of hypertension was dismissed. Mild proteinuria or damage from overload of the remnant kidney was sometimes mentioned ($n=5$) but with the message that it could be disregarded. The specific risk of having only one kidney in case of cancer, trauma or other one-sided renal injuries was pointed out in only two brochures.

Long-term check-up was mentioned in 12 booklets, one stating that this is not needed, the others recommending yearly check-ups, mainly of blood pressure and

Table 1 Common themes in 16 brochures used for written information to potential live kidney donors in 14 countries. The values represent the number of brochures containing each topic

Theme	Number of brochures
Medical limitations	16
Voluntarism	15
Advantages with living kidney donor	15
Duration of hospital stay	14
Sick-leave duration	14
Financial conditions	14
Who can donate?	13
Postoperative course (pain)	13
Short-term donor risk	13
Long-term follow-up	12
Long-term donor risk	10
Risk of graft loss	10
Risk of donor death	9
Psychological reaction	9
Psychological gain	8
Laparoscopic surgery	8

urine, or more-or-less elaborate investigations of renal function.

Psychological aspects were discussed, including inflicted stress or the possibility of depression after donation ($n=9$) as well as the benefit from seeing the relative recover ($n=8$). The risk of graft loss was discussed in ten of 16 brochures, and survival statistics were given in nine. In most instances these data were from general experience, but two centres presented their own data.

The medical benefit of living donation was expressed in various ways and in more or less detail. A better outcome ($n=14$), better quality of the kidneys ($n=7$) and less waiting time ($n=9$) were the most frequent arguments.

Great differences were noted in the declared duration of hospital stay (2–10 days) and sick leave (2–12 weeks). Four texts did not mention hospital stay or sick leave. Postoperative pain—as an indication of the post-operative course—was discussed in 13 booklets, and eight presented laparoscopic donor nephrectomy, some of these with details on hospital stay with either surgical technique.

The financial terms range from completely uncovered expenses and loss of income to a total economic coverage.

Some issues were only rarely highlighted, e.g. the possibility for female donors to give birth ($n=2$) and the issue of non-directed donation ($n=3$).

The general character of the presentation was anything from persuasive—mentioning the donors as heroes, people who save others—to almost deterring, by careful listing of all negative aspects.

The design of the brochures varied as much as the contents. Six were of full-page size, three were smaller than half a page and seven were sized in between. The median number of full pages was 11, maximum 37. In three cases, the information covered fewer than five pages and, consequently, several important questions remained unanswered. High numbers often included extra detailed information on the various investigations, the law regulating organ transplantation, or numerous illustrations. In one instance, matters such as bringing a comb and locking the door when leaving home were mentioned. The majority of presentations lacked illustrations, but a few had black-and-white pictures and three had multicoloured designs or photos.

Three brochures were sponsored by pharmaceutical companies, all three different.

Discussion

The 16 brochures included in this study are all different. They vary in size, colour, layout, language, scope, perspective and content. To some extent such differences reflect the cultural circumstances of the transplant units and the people they serve. Transplant units with new living-donor programmes need to give more basic information, justifying the procedure, and can give less detailed information, because they lack experience. This is completely understandable. The selection of information and the presentation must also be made with the general level of education in the country in mind.

Other differences between countries depend on sociocultural, legal and financial conditions for living donation [12]. Attitudes towards living donation vary in society, and this will probably be reflected in the written information [13, 14, 15, 16, 17]. Religious laws and beliefs are strong in some communities, and the role of the family in social welfare may be fundamental, thus making living donation a most natural act.

Some differences, however, cannot be explained on any of these grounds. In particular, too many brochures lack information on any of the crucial issues. The decision to become a donor is often made instantaneously on an emotional basis [18, 19, 20]. Emotions aid in processing information and influence the decision-making process [11, 12]. In this process, facts tend to be ignored or distorted. The concept of informed consent is probably an unachievable ideal [12, 21]. Great efforts are needed in attempts to overcome those difficulties. This makes information given to the potential donor, both oral and written, extremely important. The weakness with oral information is that it is totally dependent on the health carers' experience of and commitment to the issue. Written information is essential to guarantee information according to a standard and ought to be the base for the additional oral information. In our view, the information should cover as many aspects of donation as possible, even preparing the donor for rare consequences.

Obviously, the purpose of producing these prints has most often been to promote living kidney donation. Hence, some brochures are definitively encouraging, but others are neutral. Even in the case of a promoting approach, pressure is seldom exerted. The repeated proclamation that donors are heroes might be seen as an exception. Recruitment of many living donors might be seen as an achievement; however, if things get complicated the previously promoting attitude confers a greater responsibility or even guilt to the professionals involved. Even in otherwise very balanced texts, some sentences tend to direct the reader, e.g. when dealing with parents as donors they give the information that most often the mother is the donor.

Though this was not the subject of our study, we realized that the content of the pre-donation assessment differed with regard to, e.g., estimation of glomerular filtration rate and analysis of renal vascular anatomy. The conclusions drawn from the results—whether they allow donation or not—are also different.

Some of the brochures we studied fulfilled the highest standards, but others could be improved. However, the fact that they had been produced at all is laudable. Some of the centres that did not answer our request for a copy of their written information did not have any. In our view, availability of written information for living kidney donors ought to be mandatory in transplant units with a living kidney donor programme. They do not have to be produced locally, but the statements should be valid. All three brochures produced with support from pharmaceutical companies were non-commercial and professional. Therefore, we find no reason to decline offers of financial support.

This review points at several essential requirements for the contents, which should be fulfilled to enable the potential donor to make a thorough decision. We suggest the following guidelines for written information.

- Voluntarism—the fact that donation should be an act of free will
- Medical suitability
- Benefits for the recipient with a live kidney donor
- Risk of graft loss
- The assessment, and the estimated time this will take
- Postoperative course
- Hospital stay, the expected time
- Short-term donor risks—medical and psychological
- Long-term donor risks—medical and psychological
- Sick-leave duration
- Legal conditions
- Financial conditions

The information for potential donors should be given separately from general information about transplantation. The language should be easy to understand for most people and rather informal. To catch the reader's interest use illustrations, colour and wide line spacing.

Acknowledgements Our sincere thanks to all colleagues in the various transplant units around the world who provided the brochures, to Dr. Jan Kurkus for translation of the Polish text and to the medical students Pelin Dogan and Selda Sahin for translation of the Turkish text.

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