Attitudes toward xenotransplantation – patients waiting for transplantation versus the general public

Abstract The aim of this study was to survey attitudes toward xenotransplantation and to investigate whether there is a difference in attitudes between patients awaiting a kidney transplantation and the general public. A questionnaire was sent to randomly selected members of the public aged 18–75 (n = 1000) and to all patients of the same age group waiting for kidney transplants in Sweden in 1998 (n = 460). Among the public, 60% expressed a positive attitude toward receiving an animal kidney graft with the same degree of risk as a human kidney graft, compared with 66% for the patients. The proportion in favour of receiving a heart remained 60% for the public, but rose to 70% for the patients. If a human heart was not available, 61% of the public were for the use of an animal heart, compared with 73% in the patient group. A majority of the respondents would accept a transplant from an animal, provided the result and risk of infection were the same as with a human transplant. A greater proportion of patients had a positive attitude to receiving a xenotransplant than did the general public. A life threatening situation marginally increased the positive proportions.

Keywords Xenotransplantation · Attitudes · Patients · The general public

Introduction

In the future we may be able to increase the supply of organs, tissue, and cells available for transplantation by means of xenotransplantation. During recent years, the conditions for this activity have been evaluated in several countries, for example the US [7], the United Kingdom [13, 17], the Netherlands [6] and Spain [14]. In Sweden, as in other countries, there exists no legislation covering xenotransplantation. Therefore, a committee was appointed by the Swedish government to evaluate the ethical, medical, legal, and animal protection aspects of the transplantation of organs, tissue, and cells from animals into human beings. This study was carried out to investigate the public attitude to xenotransplantation. The results have previously been presented in Swedish in a different form [2].

Studies on attitudes toward xenotransplantation have been performed in different contexts [1, 3, 4, 5, 8, 9, 10, 11, 12, 15, 16, 18, 19]. In some cases, questions were asked regarding a procedure, in others, regarding individual acceptance. The rate of acceptance of xenotransplantation ranges between 40% and 75%. Sanner performed a study in Sweden in 1996 among a random sample of 1500 inhabitants ranging from 18 to 70 years of age in the county of Uppsala [15]. The response rate was 71%. The questionnaire included questions on transplantation and transfusion issues. When asked about their preferences regarding the receiving of material of different origins in their own bodies, the answers were: organs from living donors, 77%; organs from deceased donors, 69%; artificial organs, 63%; and animal organs, 40%. Another Swedish study by Lundin comprised patients who had received xenografts [9]. From
an ethnological perspective, eight diabetics were interviewed about their thoughts and feelings regarding the implantation of insulin-producing porcine islets. Lundin’s experience is that the patients have a pragmatic view according to which “survival takes precedence over any ethical or existential doubts”. In a telephone survey carried out on behalf of the US National Kidney Foundation (NKF) 1997, the attitude to xenotransplantation of several groups in society were investigated [1, 4, 12]. Among a random sample of the public (1200), 62% accepted the concept of xenotransplantation, and 75% would consider xenotransplantation for a loved one if the organ or tissue was not available from a human. There are also studies which focus on genetic technology, for example the Eurobarometer study from 1996, which was performed to survey European attitudes toward biotechnology [5]. Over 16 000 interviews were carried out with random samples of the public from 15 years of age in the member countries of the European Union. On the specific question about moral acceptance of genetic engineering related to transplants, 36% agreed or tended to agree that it was acceptable to introduce human genes into animals to produce organs for human transplants, e.g. into pigs to facilitate human heart transplants.

Several factors can influence attitudes, for example, the cultural context; whether one has experience of being chronically ill; if one needs life-sustaining treatment, or if one is waiting for a transplant. As xenotransplantation is a question of general interest for society, it is necessary to study the public opinion. However, healthy people may find it difficult to imagine being seriously ill and in need of an organ or tissue from an animal. The thought of having an animal organ in one’s body might be strange to many people. Patients with end-stage renal disease on the waiting list for kidney transplantation all have the experience of being chronically ill, of being in need of life-sustaining treatment, and of waiting for an organ transplant. One would expect them to have the insight and understanding that makes it easier for them to relate to the concept of xenotransplantation. Furthermore, a negative attitude to xenotransplantation might be modified if there was no effective alternative treatment. With this in mind, our working hypotheses were:

- A greater proportion of patients with a life-threatening disease demonstrate a positive attitude toward receiving a xenotransplant than does the general public.
- The proportion in favour of xenotransplantation is larger if there is no acceptable alternative treatment when suffering a life-threatening disease.

The aim of this study was to survey attitudes toward xenotransplantation and to investigate whether attitudes differ between patients on the waiting list for kidney transplantation and the general public. This study was approved by the regional research ethics committee at Lund University.

Materials and methods

The study populations

A questionnaire was sent both to randomly selected members of the public in the age group 18–75 (n = 1000), and also to all patients with end-stage renal failure in the same age group, who were on a waiting list for kidney transplantation in Sweden in the spring of 1998 (n = 460). The sample size of the public was sufficient to determine a difference of five percentage points.

The general public group was randomly chosen from the general population register in Sweden. Information about the waiting lists was received from each transplant unit in Sweden (Gothenburg, Stockholm, Uppsala and Malmö). Consequently, the patient study population does not include all patients with end-stage renal disease, but those patients who were eligible for the waiting list from a medical point of view and who wished to receive a transplant.

Of the public group, 596 (60%) sent in processable questionnaires; 294 (49%) were male and 302 (51%) were female. These numbers correspond to the gender distribution in this age group in the country. The mean age was 45, similar to 44 in the same age group in Sweden. Regarding the educational level of the respondents, 193 (35%) had lower education, 249 (42%) had an average education and 150 (25%) had received higher education, which corresponds with the general public aged 16–74.

Of the patient group, 398 (87%) sent in processable questionnaires; 259 (65%) were male and 139 (35%) were female. The gender distribution on the waiting-list was 287 (62%) males and 173 (38%) females. Among the non-respondents in the patient-group 28 (45%) were male and 34 (55%) were female. The mean age of the respondents and all the patients on the waiting list was 50 years. In this group, 196 (50%) had lower education, 139 (35%) an average education, and 61 (15%) had higher received education. Sixty percent underwent dialysis in hospital, three per cent underwent home haemodialysis, and more than one third had continuous ambulatory peritoneal dialysis (CAPD). The median waiting time for undergoing transplantation was 51 months (1–132).

The questionnaire

The questionnaire was designed to survey attitudes toward xenotransplantation in order to be able to reject or confirm the hypotheses. Questions were asked about the attitude toward xenotransplantation of organs, cells, and tissue. In connection with the questions, brief information was given. The information concerned the circumstances of dialysis and of allo- and xenotransplantation. Information was also given on the uncertainty regarding the transmission of viruses when transplanting organs and tissues from animals to humans, and the lack of alternative treatment in the case of a heart transplantations. Diabetes and Parkinson’s disease were described briefly. Information about the ongoing research aiming to overcome the medical difficulties related to xenotransplantation was also included. In the enclosed letter, the pig was mentioned as a potential source of animal organs, tissue or cells