Understanding Cultural Perspectives on Clinical Xenotransplantation

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The cultural and ethical consequences of clinical xenotransplantation are the focus of this article, which is directed towards the attitudes and decision-making of patients who have received xenotransplants, as well as the views of potential recipients. Xenotransplantation offers the prospect of a major medical benefit to our society but, as for all new therapeutic modalities, there are also potential risks, of which virus infection (e.g., PERV) is one well-known example.[1] When developing new therapies, it is necessary to evaluate not only the medical risks, but also the reactions of the general public. How will the public and potential recipients regard grafting from animal to human? Discussions in the medical disciplines as well as in ethical and cultural science indicate concern whether this treatment option will be acceptable to the public,[2] even though some studies carried out in recent years report acceptance by the public.[3] Nevertheless, attitudes towards xenografting are highly ambivalent. These contradictory facts must be taken into consideration when considering the attitudes of potential patients for clinical xenotransplantation (see Table 1).

The focus of this article is not on the medical issues, but on cultural concerns. For example, who will profit from, and who will be subject to, these experimental trials? What are the broad implications of medical technology's increasing ability to repair and sustain our bodies? What are the consequences of xenotransplantation for human identity, how we look upon the human body, and, not least, the outlook for mankind. This concern was expressed by a patient who received a transplant of cells from a pig, "I wonder how much from an animal can be introduced into my body before my humanity vanishes."

Two Swedish clinical trials, with direct or indirect implications for xenotransplantation, were selected for study. By the time the Swedish government set up a committee to consider the implications of xenotransplantation in 1997, cooperation between the Department of Transplantation Surgery at Huddinge Hospital and the Department of European Ethnology in Lund had already begun. Our aim was to evaluate the attitudes of patients who had been recipients or potential recipients of xenografts. The first group of patients consisted of type I diabetics transplanted with fetal porcine islets at Huddinge Hospital between 1990-93.[4,5] The second group were patients with Parkinson's disease transplanted with human embryonic neural (CNS) tissues at the University Hospital, Lund, between 1987-99, as some of these were also potential recipients of xenogenic tissues.[6]

Qualitative Methods

In general, biotechnology raises concerns about what happens when technology is used to modify nature and, particularly, our own bodies. Xenotransplantation is associated with subjective experiences, such as thoughts and emotions, that are difficult to analyze statistically. A qualitative method was, therefore, used to report our findings. In-depth interviews are a well-tried ethnological method to obtain information and knowledge about the "hidden" moral and ethical values that exist in every society. Cultural insight regarding such norms and values can provide an understanding of the complex motives that strongly influence seriously ill people, such as some of the patients interviewed.

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Table 1 | **"MORALLY ACCEPTIBILE TO INTRODUCE HUMAN GENES INTO ANIMALS TO PRODUCE ORGANS FOR HUMAN TRANSPLANTS, SUCH AS INTO PIGS FOR HUMAN HEART TRANSPLANTS?"**

COUNTRY	DEFINITELY AGREE (%)	TEND TO AGREE (%)	TEND TO DISAGREE (%)	DEFINITELY DISAGREE (%)	DON'T KNOW (%)
Belgium	15.6	23.7	20.9	27.4	12.4
Denmark	15.5	21.9	15.2	41.5	5.9
Germany	7.8	20.6	23.8	35.9	11.8
Greece	12.5	21.8	16.0	27.9	21.7
Italy	12.8	22.7	22.7	33.0	8.8
Spain	20.3	26.2	15.7	18.4	19.4
France	12.6	26.8	23.3	27.9	9.5
Ireland	9.1	14.5	18.0	34.5	23.9
Luxembourg	20.2	18.5	17.2	29.2	15.0
Netherlands	11.1	33.9	16.1	35.1	3.8
Portugal	8.2	35.2	25.1	18.2	13.3
UK	9.6	23.6	21.6	33.5	11.6
Norway	10.4	18.5	17.7	37.4	15.9
Finland	10.6	21.7	22.5	35.2	9.9
Sweden	12.4	29.4	19.8	33.3	5.1
Austria	10.0	17.0	22.6	33.9	16.6
Switzerland	6.9	19.2	26.5	41.3	6.1
Mean	**11.9**	**23.4**	**20.4**	**32.1**	**12.3**

In Eurobarometer 1996, the public was asked its attitude towards xenotransplantation. The responses to the question of the moral acceptability of introducing human genes into animals, such as pigs, to produce organs for transplantation into humans are shown. (Source: Table 6, Biotechnology in the Public Sphere, 1998.)

The interviews were directed towards key issues relating to the patients' concerns towards xenotransplantation. Examples of the type of question asked are: "Have you reflected on the prospect of receiving a transplant of animal cells?" "Have you thought about the benefits and risks associated with xenotransplantation?" "If you consider the body to have a soul, where is it situated?"

Ambivalence and Pragmatism

When discussing people's attitudes towards biomedicine, anxieties and concerns are frequently raised, and it is perhaps less common for people to express a positive and constructive attitude. A positive outlook on xenotransplantation was, however, demonstrated by the interviews. When faced with the choice between having or not having a transplant, a xenotransplant was regarded as a longed-for opportunity, while no operation at all was seen as the real risk. This attitude was found in the diabetic group who received xenografts before warnings about potential virus infection were raised. Patients with Parkinson's disease, who were well informed about the potential virus problem, continued to define xenotransplantation as a potential benefit. One patient said, "I'll do anything, I don't want to die."

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Such words express a highly pragmatic attitude, where survival is given priority over ethical doubts. In fact, in general there exists a positive attitude towards any biotechnology which is aimed towards the saving of human lives. This results in people expressing negative feelings towards biotechnology on a societal, ethical level, but accepting it on a personal level when it is a matter of a life-saving treatment for themselves.[6] A diabetic woman, reflecting on whether she would accept a kidney from a pig or not, discussed transplantation and artificial reproduction (IVF),"It feels as if there's a difference between IVF and xenotransplants. I mean, if you can't have children, maybe you're not meant to. But with a sick kidney … you die."

This patient created her own priority scale for what is natural and ethically defensible. In this hierarchy, kidney diseases and xenotransplantats are at the top, since they deal with imminent death. In this statement, and in other individual statements, there is not only set up a standard for what is ethically defensible but we also discern a reinterpretation of nature and culture, of life and death, which rests upon a special awareness of the potential of technology. The insight that biomedicine can give dying people a new lease on life makes natural death appear unnecessary and almost unnatural. Rationalizations of this kind detechnologize biomedical interventions, giving them instead the role of nature's handmaiden.[7]

Humans and Technology

The positive view of the patients was, however, not unambiguous. Expressed was also an aversion

to being influenced by what is called the "technological imperative",the concept that, if biotechnological opportunities exist, they must be used. A patient formulated his criticism, "People think you are nuts if you don't ask for help. You can't just lie there waiting to die, not when you could have a transplant instead. Nobody ought to be seriously ill, everyone has to be normal." Obviously, faith in biomedicine is strongly connected with ideas about normality and human dignity.

Humans and Animals

On another level, there existed hesitation. The pragmatic attitude of, " I'll do anything, I don't want to die!" was confronted with speculation about the danger of mixing animal with human. The patients felt uncertain whether the transplant could transmit the characteristics of the animal. One diabetic expressed her hesitation, "The cells felt okay. […] But a pig's heart! The heart is the seat of the personality and with a pig that would make it repulsive."

Another said, "The personality is in the brain. If you add a very small quantity of cells from a pig to an existing brain, that's okay. But if we were talking about replacing half of the cerebrum, then we would be replacing a large share of the individual's personality."

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The Dwelling-Place of the Self

All interviewed patients were worried about something alien taking control over their human self. They differed, however, in their view as to where in the body the personality resides. One said the heart and another the brain. It is well known in the cultural and social sciences that the self and the soul can be assigned to different parts of the body (Fig. 1).[8] Experience in Japan provides an obvious example. Since 1997, the concept of brain death has existed in Japan. Nevertheless, the public does not accept heart transplants, which require the brain death of the donor. This conflicts with the Japanese notion of the identity being situated in every part of the body, but especially in the heart. Instead, xenotransplants could serve as an alternative[9] since, in contrast to the view held in the Western world, animals are not ascribed any personality. This illustrates that cultural ideas about body and mind are important for how people and a society view medical technology.

Comment

When discussing how a society should act towards clinical trials of xenotransplantation, it is important to obtain knowledge of the attitudes of potential patients. The present study emphasizes

Figure 1. The body as an entity for Nature and human identity. The illustration shows how, in China, the body is perceived as a replica of the Cosmos. (Source: Fragments for a History of the Human Body, 1989.)

that the patient's view of xenotransplantation and his/her decision-making are only partially based on rational considerations, and can be ambivalent. On the one hand exists acceptance, but on the other, serious doubts. The positive and pragmatic view interplays with deeply-rooted norms about the dangers of mixing animal with human and of challenging nature with technology.

Such fears, however, have a tendency to fade away. In the same way that the (pharmacologically suppressed) immune system gradually integrates a donated organ, there exists a cultural immune system which can be slowly modified. What initially is assessed as threatening is gradually integrated into the culture. An illustrative example is vaccination with cow-pox virus in the 17th century, which demonstrated that people's fear of developing animal characteristics, since the vaccine contained virus from cows, was steadily transformed into perceptions of a safe and self-evident treatment (Fig. 2).

This interplay between cultural rejection and cultural integration also means that a new outlook on

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Figure 2. Transgressing boundaries between animals and humans has always been frightening to people. Vaccination with the cow-pox virus is one such example. (Source: J.Gillray, 1802.)

mankind can arise. It is tempting to formulate it like this: The biotechnological body is transformed to normality, while the natural defective body becomes abnormal.

Knowledge about attitudes and ambivalence is important and must be taken into consideration when considering clinical xenotransplantation. When discussing the role of the patient, informed consent is usually pointed out as important in the decision-making process.[10] Informed consent is, however, not always valid and meaningful if we are not aware of the fact that people's decision-making can be irrational, where personal considerations may be combined with general norms and values. To give competent information to potential recipients, medical data should be supplemented with cultural and psychological data. In this way, patients and clinicians can attain the necessary mutual understanding, and meaningful informed consent can be obtained.

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