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# Organ Transplantation Coordinators' View on the "Identity Problem"[1] of the Recipient after Xenotransplantation in Korea

Hyojung Mo *, Ivo Kwon **

**Abstract**

Xenotransplantation is considered as one of the most promising surgical innovations that could solve the current shortage of human organs for transplantation. But the possibility of xenotransplantation raised several ethical issues including identity loss or psychological crisis. We asked questions about the possibility of identity problems after xenotransplantation to a group of Organ Transplantation Coordinators (OTCs) working actively in major organ transplantation institutions in February, 2007 in Korea.

Most OTCs thought that the most common complaint of the recipients was medical and surgical complications related to the transplantation. Economic problem is one of the main issues in Korea because Korean national insurance system does not fully cover the whole medical cost necessary for organ transplantation and the patients themselves have to pay large portion of the cost.

* Department of Medical Education, College of Medicine, Ewha Womans University, Seoul, Korea mosco@ ewha.ac.kr

** MD., Ph., D., College of Law, Ewha Womans University, Seoul, Korea kivo@ ewha.ac.kr

For the responses or attitudes from the family members and friends, most OTCs thought that there would be no clear difference before and after the surgery. But they agreed that xenotransplantation would bring more serious problems than allotransplantation would for this issue. But, most important factor is the opportunity of saving life not the possibility of identity or psychological problem. The OTCs think that the recipients would prefer human organs to animal organs if the former is available. This is partly due to unresolved uncertainties or potential risks associated with xenotrans-plantation.
In conclusion, most OTCs in Korea donor concern much about the identity or psychological problems of the recipients after xenotransplantation. The issue of identity problem seems to be a trivial issue for this "to be or not to be" situation.

**Keywords**

Xenotransplantation, Identity, Attitude, Psychology, OTC (Organ Transplantation Coodinator)

## Introduction

Xenotransplantation is considered to be a promising surgical innovation that could overcome the current shortage of human organs for transplantation treatment. But this treatment has numbers of embarrassing problems such as zoonotic infection from the source animal, unknown physical harm to the recipient, and the identity problem of the recipient. (Nuffield Concil on Bioethics, 1996)[2] Especially the issue of identity problem after receiving the animal organ presents a very intriguing question about the recipient's future quality of life. This issue could be involved not only with a certain psychological crisis but also with a possibility of social discrimination and alienation.

The identity crisis after Xenotransplantation is mainly related to the view of the recipient himself on his own body, and the view of others surrounding him. The fact that he has an animal organ (or tissue) in his body will also have influence on the view. But so far we do not have anyone who have really gotten organ xenotransplantation yet, and know little about the possibility of identity problems.

Some investigators reported that the allo-organ received patients complained of experiencing identity crisis or psychological difficulties after the transplantation. (Mai FM, 1993)[3] But the number of such reports is so limited that we are not sure if such phenomenon is a common one. It is not an easy question to answer because "identity crisis" is caused by a very subjective inner sensation. It is hard to prove or to measure the concept of "identity." However, the experiences of the allotransplantation recipients will shed light on this aspect of xenotransplantation, and we can take an advantage of the experiences.

In this survey, we asked questions about the possibility of identity problems after xenotransplantation to a group of Organ Transplantation Coordinators (OTCs) working actively in major organ transplantation

institutions in Korea. They are thought to be the most appropriate group who could answer this difficult question, for they best know the recipients' condition and psychology through the process of the recipient selection, transplantation operation, and follow up program. Of course

Questionnaire Form: written in Korean

1. How long have you been in your career as nurse and OTC?
2. What kind of organs does your institution transplant, and how many follow up recipients are in your institution?
3. What are the common complaints of the follow up recipients in your institution? Choose 2 items.
4. What are the major concerns of the recipient? Choose 2 items.
5. Have you ever met the recipients complaining identity problems or personality change after organ transplantation? If Yes, to 5-1, and 5-2.

5-1. What is the most common organ inducing identity problems in the recipient?

5-2. How are the identity problems expressed in the recipient?

6. Do you think that the family members or friends are psychologically responding to the recipient as the same way as they did before the transplantation?
7. What would be the response of the recipient to xenotransplantation compared with allotransplantation with regard to identity problems?
8. Do you think that the response of the family members or friends would be identical after xenotransplantation?
9. What is the psychological response of the recipient after xenotransplantation?
10. Do you think that xenotransplantation would be an alternative treatment for the patient in spite of the risk of identity problem if some biological obstacles are overcome

their answers could not fully reflect the recipients' own thoughts and feelings, but in a certain point of view, their views and opinions are thought to be more objective in evaluating the possibility of identity problems rather than those of recipients are. They are fully experienced medical professionals and could see the whole situation from group perspective not from individual perspective. Their opinion could be valuable in conceptualizing the possibility of identity problems after xenotransplantation.

## Method

A paper questionnaire form consisted of 12 items was distributed to the OTCs attending the KAOTC (Korea Association of Organ Transplantation Coordinator) meeting on 15th February, 2007 in Seoul, finally 28 questionnaires were collected. The total number of OTCs in Korea is about 70 in 2007. There are 74 registered transplantation institutions in Korea, but 35 of which are transplanting more than 4 kinds of organs defined in the "Organ Transplantation and Brain Death Act" in Korea.[4] They employ full-time OTCs for the management of organ transplantation. The other institutions transplant cornea, kidney, bone marrow, or one or two of them. Such institutions usually employ part-time coordinators.

The answered raw data were put into Microsoft Excel™ and analyzed by simple descriptive statistics.

## Results

### 1. Professional career of the OTCs responding to the questionnaire

The average term of career as nurse of the respondents is 11.3 year, and the average term as OTC is 4.9 years. The number of respondents who

have been working as OTC less than 5 years is 12, 5 years to 10 years is 7, and more than 10 years is 2. 7 respondents did not answer this question.

Table 1. Term of Career

| | Career term as nurse | Career term as OPC |
|---|---|---|
| Less than 5 years | 7 | 12 |
| 5~10 years | 7 | 7 |
| More than 10 years | 13 | 2 |
| No response | 1 | 7 |
| Total | 28 | 28 |
| Average | 11.3 | 4.9 |

**2. Kinds of organs**

The most frequently transplanted organ was kidney (average 1308.3 per institution where the responding OTC were working), and the next was liver (average 388.6). Heart transplantation cases were only 36.4, and pancreas 22.4. Lung cases were 5. These numbers included both living donor cases and brain death donor cases. In Korea, over 90% of organs for transplantations are from living donors, so the numbers of kidney and liver transplantation cases are relatively large.

Table 2. Average Number of Cases

| | Number of Institutions | Average Number of Cases |
|---|---|---|
| Kidney | 27 | 1308.3 |
| Heart | 14 | 36.4 |
| Lung | 5 | 5 |
| Liver | 19 | 388.6 |
| Pancress | 14 | 22.4 |
| Cornea | 5 | 561.0 |

### 3. Common complaints of the recipients in follow up program

To the question "What is the most common complaints of the follow up recipient in your institution?" 13 OTCs chose one or two items while 15 OTCs gave no response. The latter might not have seen any serious complaint from the follow up patients. The most frequent complaint of the recipients was "surgical complications or other health related problems (48.8%)". The next was "complications related with immuno-suppression (36.6%)" and economic problem related with transplantation (12.2%). No one pointed out "discrimination from family members or friends after transplantation."

Table 3. Common Complains of the Recipients

| | Number of response | Relative ratio |
|---|---|---|
| Surgical complications | 20 | 48.8 |
| Immunosuppression complication | 15 | 36.6 |
| Economic problem | 5 | 12.2 |
| Discrimination of family members | 0 | 0 |
| Others | 1 | 2.4 |
| Total | 41 | 100.0 |

### 4. Major concerns of the recipient

To the question "What are the major concerns of the recipients?" 24 OTCs (71.4%) responded and chose 2 items. The most serious concern was "recurrence or surgical complication" (43.8%). The next was the concern of transplantation failure (33.3%). Economic problem (12.5%) due to medical fee and bad health condition (10.4%) was followed.

Table 4. Major Concerns after Organ Transplantation

| Kinds of concern | Number of response | Relative ratio |
|---|---|---|
| Rejection of the organ | 16 | 33.3 |
| Bad health condition | 5 | 10.4 |
| Recurrence or complication | 21 | 43.8 |
| Economic difficulies | 6 | 12.5 |
| Identity crisis | 0 | 0 |
| Total | 48 | 100.0 |

**5. Experience of identity problem cases**

To the question "Have you ever met a recipient complaining iden-tity problems or personality change after organ transplantation?" 13 respondents (46.4%) said "Yes." Kidney and liver were thought to induce identity problems frequently, but the heart was the third. But this number has its limitation in analysis because the OTCs who had experienced heart transplantation were only half of the whole respondents.

The ways of expressing of identity problems were diverse. "Depression" is the most frequently seen (38.1%). "Anger" (28.6%) and psychosomatic symptom like insomnia (23.8%) are also frequent. Personality

Table 5. Organ inducing Identity Problem

| | Number of response | Relative ratio |
|---|---|---|
| Heart | 3 | 20.0 |
| Kidney | 6 | 40.0 |
| Liver | 6 | 40.0 |
| Lung | 0 | 0 |
| Pancreas | 0 | 0 |
| Cornea | 0 | 0 |
| Total | 15 | 100.0 |

Table 6. Expression of Identity Problem

| | Number of response | Relative ratio |
|---|---|---|
| Anger | 6 | 28.6 |
| Depression | 8 | 38.1 |
| Personality change | 1 | 4.8 |
| Psychosomatic symptoms | 5 | 23.8 |
| Others | 1 | 4.8 |
| Total | 21 | 100.0 |

change after transplantation is relatively rare (4.8%).

## 6. Psychological response of the family members or friends to the recipient

The psychological response of the family members and friends to the recipient after transplantation was basically the same as the one "before transplantation" or somewhat different (42.9% each). Only 2 OTCs responded there was a meaningful difference before and after transplantation in the attitude of families and friends.

Table 7. Psychological response of the family members / friends

| | Number of response | Relative ratio |
|---|---|---|
| No change | 12 | 42.9 |
| Some what different | 12 | 42.9 |
| Quite different | 2 | 7.1 |
| No idea | 1 | 3.6 |
| No response | 1 | 3.6 |
| Total | 28 | 100.0 |

## 7. Identity problems after xenotransplantation compared with allotransplantation

More than half of the respondents (57.1%) thought that the identity crisis or psychological problem would be more serious in xenotransplantation compared with allotransplantation. But 39.3% of the respondents thought that it would be almost same both in xenotransplantation and in allotransplantation.

Table 8. Identity Problem after Xenotransplantation

| | Number of response | Relative ratio |
|---|---|---|
| More serious | 16 | 57.1 |
| Identical | 11 | 39.3 |
| Less serious | 0 | 0 |
| No idea | 1 | 3.6 |
| Total | 28 | 100.0 |

## 8. Psychological response of the family members or friends after xenotransplantation

Most respondents (53.6%) expected that the psychological response of the family members or friends to the recipient would be somewhat different after xenotransplantation compared with the one "before

Table 9. Psychological response of the family members / friends

| | Number of response | Relative ratio |
|---|---|---|
| No change | 7 | 25.0 |
| Some what different | 15 | 53.6 |
| Quite different | 6 | 21.4 |
| No idea | 0 | 0 |
| Total | 28 | 100.0 |

transplantation." But 25% of the respondents thought that there would be no change whilst 21.4% of the respondents expected serious changes.

### 9. Preference of the patient if xenotransplantation be available

Over half of the respondents thought that the potential recipient would show no preference to the source of the necessary organ (53.6%). Availability is the most important factor to the potential recipient, and the source does not matter. Despite this, most OTCs agreed to the opinion that the potential recipient would prefer human organs to animal organs (46.4%).

Table 10. Prefererence of the patient

| | Number of response | Relative ratio |
|---|---|---|
| Prefer allotransplanation | 13 | 46.4 |
| Prefer xenotransplantation | 0 | 0 |
| No preference(it doesn't matter) | 15 | 53.6 |
| Total | 28 | 100.0 |

### 10. Is xenotransplantation to be available as an alternative treatment in spite of ethical obstacles like identity problems?

Almost all respondents thought that if xenotransplantation were technically available, it should be employed as an alternative treatment in spite of the possibility of "identity problems."

Table 11. Attitude toward xenotransplantation as an alternative treatment

| | Number of response | Relative ratio |
|---|---|---|
| Yes | 27 | 96.4 |
| No | 0 | 0 |
| No idea | 1 | 3.6 |
| Total | 28 | 100.0 |

## Discussion

This survey did not reflect the opinion of all the OTCs working in Korea; moreover it did not directly investigate the patients' or recipients' view on this issue. But most OTCs who responded to this survey were working in the major organ transplantation institutions in Korea, and their experiences must generally show the recipients' perspective.

Most OTCs think that the most common problems complained by the recipients are medical and surgical complications related to the transplantation. The personal identity or psychology related issues are thought to be relatively minor. This phenomenon can be understood by the fact that most recipients whom they met were kidney transplant patients from living donors.[5] Economic problem is one of the main issues in Korea because Korea's national insurance system does not fully cover the whole medical cost necessary for organ transplantation, and the patients themselves have to pay a large portion of the cost.

Concerning the possibility of identity problem only one respondents pointed out "personality change." For anger, depression, and psychosomatic symptoms are often seen among other patients facing life threatening diseases, they are not considered to be specific cues of identity problem. More researches should be done to understand various ways of addressing identity problem.

Concerning the responses or attitudes from the family members and friends, most OTCs thought that there would be no obvious difference between before and after the surgery. But they agreed that xenotransplantation would bring more serious problems than allotransplantation would for this issue. However, they thought that the patients would get the any organ necessary for their life sustenance regardless of its source in the life threatening condition. The most important factor would be the opportunity of saving life, not the possibility of identity

loss or psychological problem. Similar phenomenon was seen in studies in Netherlands and Mexico; in Netherlands almost all of 61 patients waiting for kidney transplantation were willing to accept xenotransplantation if it is the only possibility in the life threatening situation. (Kranenberg, 2005)[6] In a Mexican study which assessed 10 insulin dependent diabetes patients who received porcine islet cells, there were no troubles regarding the graft origin. (Teran-Escandon, 2005)[7]

Despite this attitude, the OTCs thought that the recipients would prefer human organs to animal organs if the former is available. This is partly due to unresolved uncertainties or risks associated with xenotransplantation. In a French study, the potential recipients suffering from diabetes show their reluctance for the risk of infection or other uncertainties. (Deschamps, 2003)[8] However, the OTCs in Korea perceive the future feasibility of xenotransplantation in a very positive way. This kind of attitude is also seen among primary health care professionals in Spain, where 79% of responded doctors favored xenotransplantation. (Conesa, 2006)[9] In Korea, according to one survey, Korean's attitude toward xenotransplantation also showed similar positive view on xenotransplantation. 61.6% of respondents were positive to xenotransplantation while 30.8% of them were negative. (Kwon, 2005)[10]

In conclusion, most OTCs in Korea do not concern much about the identity crisis or psychological problems among the recipients after xenotransplantation. Although the potential patients would prefer human organs, in the life threatening condition, the source of organ would not matter to them. The number of brain death donors is relatively small in Korea, and most patients on waiting list are still suffering from scarcity of the available organs. It is so natural that the OTCs feel the necessity of alternative organ sources in this situation. One of the OTCs wrote down on the survey form. "The source of organ really does not matter to the dying patient in need of organ. They would make every effort to get any

kind of organ if possible." The issue of identity problem seems to be a trivial thing to this "to be or not to be" situation. Most OTCs' views reflect this understanding.

## NOTES

1. I use "identity problem" in a multiple meaning. It means any psychosomatic discomfort after xenotransplantaton due to distorted self body image, foreignness feeling of his own body, anxiety for the other people's view on his own condition. But this concept has to be analyzed in more accurate definition.
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