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Study of the immigrant population's attitude towards organ donation in two groups from Pakistan and Morocco

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➤ Abstract

Organ transplantation may not be done without the awareness and active participation of the community: no donor organs, no transplants. In the past few years, Spain's growing immigrant population has posed new challenges in this field, and calls for reflection upon the most appropriate forms of intercultural dialogue.

In consideration of the very special implications of organ donation, our interest was to define, compare and contrast the values and beliefs of two groups from Pakistan and Morocco.

➤ Introduction

The donation-transplantation process calls for a dialogue that has been remarkably fruitful in Spanish- and Catalan-speaking communities: the national index of cadaver donors per one million inhabitants (34,6 according to 2004 data) is the highest in the world. As a result, transplant activity in Spain has increased considerably in the last two decades.

In spite of the confident figures, there are never enough organs; some people still oppose donation, and demand is greater than supply: There are quite a number of patients on the waiting list for transplantation, and some die before an organ becomes available.

In this atmosphere of moderate optimism, a new panorama has started to take form since the 1990's: the increase in immigrant population, which requires a general effort by the receiving society in terms of housing, education, social services and health care. It is precisely in the realm of health care delivery that specialized health operators and the incoming population will eventually meet to start the donation-transplantation process.

➤ Motivation for the research and field work

As an anthropologist and intensive care nurse I became interested in organ donation and learnt of cases where people from non-Western European cultural milieus have refused donation. In my workplace I have also heard comments like "Gypsies are ready to receive organs but will not donate"; "Immigrants give irrational explanations to justify their refusal", "The Chinese never donate and Moroccans are no different". So I asked myself, are there any differences in attitude towards organ donation between the gen-

eral population and newcomers? How do beliefs, values and personal experience influence decisions in this matter?

➤ Choice of the population sample

Considering that immigrants to Barcelona come from all over the world, we limited the investigation field to two groups: Pakistanis and Moroccans.

Our choice accounted for the fact that most immigrants from Pakistan to Spain reside in Catalonia, 90% in Barcelona, and that Moroccans are the largest immigrant community in both Catalonia and Spain.

Another important factor is that Islam is a common denominator of both groups. In Pakistan 97% of the population is Muslim, mostly Sunnis. In Morocco, Islam is the state religion according to the 1992 Constitution and 99% of the population is Muslim, again mostly Sunnis.

➤ Aim and Methodology

The field methodology was ethnographic. We used observation and open interviews that followed a general guideline but whose final design was given by the informant's attitude, opinions, ideas and concerns. The questions regarded degree of knowledge and opinion about donation and transplants, system of beliefs (religion, perception of death, body integrity), degree of knowledge and opinion about the organ trade, and experience with the Catalan public health system.

The sample consisted of 5 participants from Morocco (one female, four males), six participants from Pakistan (2 females, 4 males) and two imams (religious authorities from a praying/ centre/ mosque in Barcelona).

The inclusion criteria (except for the imams) were:

- immigrants living in Barcelona
- from Pakistan or Morocco
- over 18 years of age (any sex)
- Spanish or Catalan-speaking

➤ Analysis of the interviews

The analysis of the interviews reveals a generally positive attitude towards donation. The subjects justify the legitimacy of organ donation and its ethic and social value within the context of the humanitarian values of Islam, the teachings of the prophet Mohammed, and verses in the Koran such as: "If anyone saves a person it will be as if he

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has saved the whole of humanity," "Good actions on Earth will find compensation in Paradise". One of the subjects said, "Religion says that if you can help others you must do so, even after you have died". And another one said that donation seemed "ideal" because whatever we do in order to save somebody's life is right, with the only exception of killing somebody else.

The value given to the intention of helping others is stronger than the preoccupation for the fate of the organs. One subject said: "I know that my eyes would not go to a dog but to a human being, no matter whether rich or poor, it's a person". Another one: "The intention behind donation is to save a person's life, no matter whether Spanish, Rumanian, Portuguese, Pakistani, Hindi...". Still another went beyond that and said: "The aim of donation is always to do good to the human being: on these grounds, both transplantation and investigation with donated organs is positive and advisable. Another one said that Islam favours donation, "rewards" donation, for there is a general rule that says: That which is good for people, and is reasonable and logical, (donation of blood and organs, use of condoms) is certainly advisable, that which is bad for people (alcohol, drugs) must be avoided. With an even wider view, another one declared that the value of donation is intrinsic to the values of Islam: "If there is nothing in the Hadith or in the Koran against donation, then one should not be restrictive with an issue that God has left open. One of the good things about Islam is that there are not many prohibitions. God has left everything open so that humans may settle things among them, for each age is different".

Again there was not much difference between groups in several other issues.

a) They express confidence in Islam, which is an identity factor and a fundamental source of values: "I've been living here for four years now, and I don't smoke or drink". Or "The concept of religion here is different. The Muslim religion is a concept of life, is a theory, it regulates life". A female subject said, "I don't wear a shawl but I'm a Muslim, I wear it just when I want to". She felt Muslim, not from the way she dresses or from the frequency of her prayers, but because "I harm nobody, I love and respect everyone". Another one said that Islam gives him some values and emotional stability. Religion is something personal and private, and the fact that he believes in Allah does not determine his relationship with others, Muslims or not.

b) They interpret the sources of Islam, to various degrees, in a literal fashion. They firmly believe in the sacredness of the prophet Mohammed and the Koran. The belief in a life after death, in Paradise if one has been a good person or in Hell if one has acted wrongfully on Earth, is

common to all the subjects even in those who define themselves as "not very religious". As for the authority they give to imams, and the confidence they place in them there was a wide range of opinions: "He who has a long and bushy beard is imam". "I respect imams very much, but I respect humanity even more"; "The imam is important, he is a central figure in the community of believers. From the human point of view, he is an ideal person, healthier, less conflictive, and shows the highest wisdom for he gives us the answer to all our questions. We respect him for his wisdom, not for his face or beauty or money". But then another one said: "I pay no heed to imams. More than 90 % of those who play the religious man, who show off as imams, as people who know, well they know nothing. You need to study a lot to know and interpret the Koran".

c) Participants know the death rituals of Islam and attach importance to them. There is the common interest to be buried according to their beliefs or by their families, either in their country of origin or here, in a proper cemetery fit for Muslims. One of the subjects said: "We will do whatever is necessary to have a suitable space, that we may buy or rent, it doesn't matter, but it has to be a decent cemetery where all Muslims, rich or poor, may be buried". They all agreed that Islam recommends that the burial must follow quickly after death. One said: "I think that a dead body deserves dignity and must be interred as soon as possible".

d) The subjects mostly agree that in Islam the human body is sacred and must be looked after, but upon death, its importance varies among the subjects. A subject said that the important thing upon death is the soul: "Body means nothing. When a person dies, the body mixes with the soil". Another one believes that "The body is a gift from God, it must be kept healthy, even tattoos are banned. When we die, the body must still be respected". Another affirms that, even though in Islam the body is sacred, it may be used if it serves to save a life. It is a question of priorities.

As regards the organ donation process, people from both groups:

a) Know more about donations by living people than about cadaver donors (we should not forget that living donor kidney transplants are a worldwide practice).

b) Show partial ignorance about, or some resistance to, the concept of "brain death," but it is not an unknown subject. Somebody said, "brain death is when the brain dies on you. For me death is absolute death, not when an organ works and another doesn't. I cannot consider that somebody has died until they have become wholly paralysed,

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both inside and outside". Someone else said, "There are people that remain like that, dead but alive". The same subject believed that it is very difficult for the general population to understand this concept. That is why it is important to inform people, for instance, through a specialist on television, or through the imam in the mosque. "I think the mosque is a good place to speak about these things". Another two subjects said, "Brain death occurs when the body goes on living but the brain is dead"; And "A person is clinically dead when the body is working through the machines, but there is no communication whatsoever with the world".

Finally, and again with no difference among the groups,

a) They believe there exists some sort of organ trafficking and they expressed disgust. One said he had heard of a case in Morocco: "in 1987 or '88 they removed kidneys from children," and he also knew that in the United States the transplantation of organs "has become a market".

b) They reject the idea of organ trading. One said, "Donation is ok as a humanitarian action, not to get money out of it".

c) As a rule they think it is important that people discuss the subject and take a stand. In this way one is ready and knows what to do if the time comes when one has to decide whether or not to donate the organs of a deceased relative. One subject said that it was not useful to keep a donor card. "I believe there shouldn't be much red tape around these things. You know what the will of the people around you is, by talking about the subject".

d) They expressed their satisfaction with the public health system in Catalonia; no more than the usual complaints (long waiting times to see a specialist or for diagnostic tests). Apart from a lady who declared, "The first problem is that I have a racist doctor," none of the participants feel discriminated as a result of their being immigrants.

As for the imams, they both recognized that there are two lines of thought regarding organ donation for transplantation purposes. The principle behind the first –which does not explicitly recommend donation- is that the body is sacred and belongs to God. Therefore human beings must take care of it and may not dispose of it as they please, not even after death. The body, be it alive or dead, must never be damaged or manipulated. One of the imams quoted a hadith of the prophet Mohammed: "To break the bone of a dead person is the same as breaking the bone of a living person". Following this line, Islam refuses incineration for it damages the dead body and because, as one subject said, "Dust we are and to dust we shall return".

This imam added that donation refusal would prevent organ trafficking and trading. Although he was not convinced about the appropriateness of donation, he said he does not condemn but respects those who are clearly in favour of donation. If a person of his community consulted him about the subject, he would recommend that he decide according to conscience. If he were consulted about whether it is correct to accept a transplant to replace a damaged organ, he would definitely recommend people to do so, because one has to do whatever possible to protect life, and in this case body manipulation would be advisable.

The second line of thought explicitly recommends donation. The principle supporting this stand is that God cherishes and rewards positive actions (and also the intention of performing a good action) oriented towards saving a human life. If the operation is well managed, showing respect for the body, it is good to donate organs that will be used to save lives.

This is the position taken by the other imam we interviewed. He also said that for a donation from a cadaver it is necessary to have the donor's authorization or the authorization of the potential donor's family. He said, "This is the way to avoid the organ trade, for they are killing healthy people, healthy children to take their organs; not here in Barcelona but in other places". He emphasized that is it all right to donate the organ, not to sell it. If he were asked by the people of this community about donation, he would personally recommend it.

➤ Conclusions

Certain factors may negatively influence the attitude towards organ donation. These include the lack of knowledge about some phases of the donation-transplant process, having news (accurate or not) about the marketing of organs, negative events associated with the personal migratory experience and direct rapport with sectors of Islam that do not advocate donation. All this considered, however, donation is largely perceived as constructive and encouraged by Koranic teaching: "to save the life of a human being is like contributing to save all of humanity".

The knowledge of how the cultural and religious context of Pakistani and Moroccan immigrants can impinge on their attitude towards organ donation may come in useful in the direct relationship between the medical staff (transplant coordination) and the immigrant population. The basis of mutual understanding is mutual knowledge. Knowledge is what makes us shed our preconceptions, the necessary condition for a true dialogue between different cultural environments.

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The situation where persons coming from all over the world are confronted with organ donation and transplantation as a therapeutic option reminds me of what Ma. J. Buxó said in 2004, that intercultural bioethics is both situational and contextual, and calls for the transversal

discussion and understanding of that which worries and affects citizens and experts in terms of global health.

In short, intercultural bioethics works to bring together scientific, economic, social and moral progress with values such as justice, equity and respect.

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