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# Transplant Coordinators and Communication With Potential Organ Donor Migrant Families in France: An Exploratory Qualitative Study

G. Lesoeurs, J. Cossart, C. Olivier, T. Ferradji, and the Working Group "Problématique Transculturelle du Don d'Organes, Fondation Greffe de Vie-Roche," in collaboration with Agence de la biomédecine

ABSTRACT

Donor transplant coordinators often face organ donation refusals by migrant families in France. A multidisciplinary Working Group was asked by "Fondation Greffe de Vie" and Roche Company, in collaboration with the French national agency "Agence de la Biomédecine," to design a support program to improve communication between coordinators and families from other cultures upon the death of a family member who could be a potential donor. CerPhi was asked to conduct a survey of 30 coordinators in 22 French establishments. Most of the interviewed coordinators indicated that cultural differences complicate communication with families, leading to a higher proportion of organ donation refusals than among the local population. Coordinators are looking for a better knowledge of cultural and religious patterns as well as pertinent transcultural behaviors to improve their communication with families in the painful moment of raising the question of organ consent.

TRANSPLANT COORDINATORS are frequently powerless when faced with the refusals of migrant families with whom they must discuss issues without always understanding them. This problem has led to the double drawback: a prolonged wait for people awaiting a transplant and the families' feelings of having been misunderstood for their decisions. To better understand the expectations of transplant coordinators faced with such issues, in early 2007 our Working Group asked CerPhi to conduct a survey of 30 coordinators in 22 French hospitals or institutions. The aim was to design a support program for communication with families from other cultures upon the death of a family member who could be a potential donor. After preliminary interviews, we noted certain points to be confirmed in a wider population. The reasons for migrant families' refusals would appear to be linked to a fear of mutilation of the body, to doubts regarding the reality of the death of the family member, and also to a difficult relationship with the host culture. Cultural reasons would appear to be linked to religion, beliefs, taboos, or responsibilities. Refusals based on cultural benchmarks are particularly prevalent among migrant populations who remain faithful to their culture of origin and in communities where religious norms guide thoughts and practices.

From the Society for Research in Medical Anthropology, Paradou, France; Hôpital Cochin, Paris, France; CerPhi, Centre d'Etude et de Recherche sur la Philantropie, Paris, France; and Department of Psychopathology, Hôpital Avicenne, Bobigny, France.

Members of the Working Group "Problématique Transculturelle du Don d'Organes, Fondation Greffe de Vie-Roche": C. Antoine, Renal Transplantation Unit, Hôpital Saint Louis, Paris; S. Beloucif, Anaesthesia and Intensive Care Unit, Hôpital Avicenne, Bobigny; Y. Caillé, Fondation Greffe de Vie, Paris; J. Cossart, Organ and Tissue Transplantation, Hôpital Cochin, Paris; C. Dupre-Goudable, Nephrology, Hôpital Rangueil, Toulouse; T. Ferradji, Department of Psychopathology, Hôpital Avicenne, Bobigny; A. Houlou, Department of Linguistics, University Lille III, Lille; G. Lesoeurs, Medical Anthropology, SOCRAMED (Société de Recherches en Anthropologie Médicale), Paradou; D. Maroudy, Organ and Tissue Transplantation, Hôpital Saint Louis, Paris; L. Mendes, Communications Unit in Transplantation, Roche, Neuilly; J. di Sciullo, Communications Fondation Greffe de Vie, Paris; A. Tenaillon, Pôle Stratégie Greffe, Agence de la biomédecine, Saint Denis; A. Vaccaro, CerPhi, Centre d'Étude et de Recherche sur la Philanthropie, France.

Address reprint requests to Guy Lesoeurs, MSc, SOCRAMED Chemin des Deux Bessons, F-13520 Paradou, France. E-mail: cerveauxsfi@wanadoo.fr



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The removal of an organ may conflict with traditions, especially if bodies are to remain intact after death. Finally, the choice of the person best placed to obtain the consent for the organ donation is linked to the way the family is organized, namely, the authority of the father, brother, or uncle.

In this study, we explored the real-life experience of hospital organ and tissue removal teams to highlight communication difficulties with migrant families regarding organ or tissue removal, and to identify good practices and expectations regarding information and training. Another aim of the study was to identify the causes of migrant family refusals to find ways to improve relations, coordinator communication, and family support.

## MATERIALS AND METHODS

This exploratory qualitative pilot study was conducted over the telephone with a semidirective interview guide. The telephone interviews performed by a professional Institute CerPhi interviewer were recorded after consent was obtained from the interviewees, with the guarantee that the answers would be treated anonymously. Thirty coordinators from 22 establishments in mainland France were interviewed with prior notice given to their managers. Each interview lasted on average 40 minutes. The survey was conducted from March 1 to April 15, 2007. The sample, which was nonrepresentative of all hospital coordinators, consisted of people selected randomly from a list of most hospital coordinators in France. It included 6 men and 24 women, 8 of whom were physicians and 22 nurses.

The surveyed people had been in their positions for 1 to 20 years. The self-reported time spent in coordination varied from 20% to full time. The self-reported number of organ or tissue removals per year ranged from 3 to 30 or more. The self-reported rate of organs obtained in relation to the number of interviews with families (of all origins) varied from 50% to 70%.

## RESULTS

### Attitudes of the Coordinators

Besides the range of profiles, and whether the situations were transcultural* or not, the interviewed coordinators had the following attitudes in common: a strong involvement in a desired and chosen position; it is a difficult but exciting profession, and they contribute daily to its innovation and promotion. A commitment in favor of organ or tissue removal related to their work, the manner in which they experience their work, and the information and training tasks they may undertake inside and outside the hospital. A positive attitude toward the removal of tissues and organs combined with strong values of life, progress, solidarity, and citizenship. A reaction to the refusal to remove organs or tissues as suggesting either a lack of solidarity or a resistance to the idea of donorship; donations must be universal and eventually routine.

### Interview With the Families (Migrant or Not)

The coordinators point out that this is a moment of shock and sadness for families. The families are confronted with new realities and reasons that disturb traditional systems of perception. This is even more true when people have previously been badly or not very well informed. They are therefore asked to answer major questions at a time when they are least able to do so.

The coordinators believe that these requirements are difficult to accommodate because they must explain difficult, ambivalent concepts in a context in which understanding will be difficult, to people who have been badly informed, all while providing urgent support that requires time. This is the time and place when the personal and professional competence of the coordinator is established and confirmed, including the ability to follow procedures while respecting the law, putting the individual at the center of his or her concerns. The coordinator must, in fact, play a paradoxical role, simultaneously taking charge of any individual or group in an individualized manner and treating all cases in an identical manner, with no a priori concerns and without overriding basic rights.

### Relationship With Migrant Families

Even though the situation is not necessarily experienced differently compared with people of the "local" culture, the situation presented by families of other cultures was judged to be more difficult and more complicated by the majority of coordinators, especially when there were systematic refusals. However, the idea of different treatment based on cultural idiosyncrasies appears to clash with secular and egalitarian principles and to question the value system of some coordinators. This explains the reluctance of some coordinators to handle the transcultural situation in a specific manner.

For most coordinators, all "generic" difficulties of communicating are greater when dealing with migrant families due to the presence of strong cultural concepts: upheaval related to grief, difficulty integrating new ideas and deciding; protective behavior toward the deceased in relation to the hospital; feeling of reduced solidarity with the society of the host country; and the need to recommit to rites and reaffirm traditional values. Thus there appears to be a clear difference between the perceptions and values of biomedical professionals and those of the migrant families.

### Question of Religion

Whether implicit or explicit, the reference to religion seemed to be at the center of these difficulties, because it is

*According to Moro et al,[5] the word "transcultural" (or metacultural) is used when the medical person and the family of the donor are of different cultures, but the (specifically trained) medical person understands the concept of "culture" and applies it. The word "intracultural" is used when the medical person and the family of the donor are of the same culture. The word "intercultural" is used when the medical person and the family of the donor do not belong to the same culture, but the medical person is familiar with the family's culture and uses this knowledge as leverage.

a reason that is frequently invoked for definitive refusals. This poses a problem of admissibility to hospital teams doing organ and tissue removals, since they are familiar with the official favorable positions of the major religions. The recourse of families to religion appeared to coordinators to be a practical cover for their inability to decide or to disguise their personal opposition.

### Factors Involved in Difficulties

The coordinators analyzed the transcultural situation based on 3 factors. First, the weight of tradition and traditional perceptions which, even outside of the realm of religion, do not allow the removal of organs or tissues. This is coupled with the fear that the rites of death cannot be performed in accordance with their rules. Second, the necessity for the individual to conform to his or her culture of origin due to fear of judgment and reactions of the group and/or due to concern over not clashing with the group. Third, a lack of solidarity which is linked, for some coordinators, to the level of instability and/or to the lack of social consideration that these families can feel; for other coordinators, it is linked to communitarians that shock medical professionals.

### Different Populations According to Regions

The communication difficulties of the transplant coordinator may be encountered to varying extent among different populations depending on the hospitals and the population pools. Nevertheless, not all populations are perceived as posing the same level of difficulty, for quantitative reasons (frequency of communication with these families) and for qualitative reasons (intensity, number of associated difficulties during the discussion with the same family).

### Perceptions of Medical Professionals and Families Are Not in Synchronic

On the one hand, medical professionals trained in the biomedical sciences assert the values of a Western scientific approach with a rational analysis of the biological body and the ethics of medical progress. On the other hand, families with a traditional culture believe in a symbolic body that cannot be dissociated from the soul and which must be preserved in its integrity, with death considered unavoidable.

## DISCUSSION

The coordinators emphasized the fact that the work of sensitizing communities must be done in advance. First, public education to demonstrate the need to remove organs as vital for the communities. Second, a better consideration of cultural traditions by the hospital.[2] Third, develop the role of coordinators to introduce ideas and open a dialogue between the two systems to avoid a head-on collision. Fourth, train hospital teams to evaluate or manage cultural differences with appropriate behavior. Fifth, coordinators would like specific training in the transcultural approach and areas for dialogue and experience-sharing.

In conclusion, the data collected to better understand the more frequent refusal by migrant families to donate organs compared with the local population suggested that it is necessary to consider different parameters, especially: the relationship of the individual and/or the family to its sociocultural group and the hospital institution; the mental perceptions of the consequences of organ removal; the symbolism attached to the body and to different organs in various cultures;[1] the perceptions of death and associated rites; the religious dimension put forth as a pretext for refusal, even though none of the major monotheistic religions oppose it; and the possible mistrust of the migrant with regard to the health system/hospital due to cultural differences.

This exploratory qualitative survey allowed us to confirm that cultural aspects increase the difficulties of teams that are not trained by hospitals, which are themselves powerless before these cases.[3] We noted their reluctance to talk about the problem for fear of making differences that would be contrary to the principles of universality and secularity in medical care. The study has also shown that the problem is located upstream of the situation between coordinators and families, with the necessity of sensitizing uninformed or badly informed communities.[4]

We have therefore demonstrated the necessity of training coordinators to assume a "transcultural posture" so that they can better enter into relationships and manage their possible uneasiness in front of the culture of the "Other," to avoid the misunderstandings and frustrations of families and those of the coordinators themselves, and to communicate about organ and tissue donation at the community level.

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