Important Social Factors that Affect Organ Transplantation in Islamic Countries

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Social attitudes and beliefs have direct and strong impact on people's acceptance of organ donation and brain death, and therefore affect the entire practice of organ transplantation. The views differ from one society to another, and they at least partially explain regional variations in the world with respect to success of organ transplantation.

Social attitudes and ethics in Islamic countries are closely intertwined with Islamic tradition, teachings and heritage. These positions are strongly adhered to in many Islamic countries, and by Moslems who live in countries that are not predominantly Islamic. We feel that transplant physicians and transplant coordinators should be aware of these factors when dealing with potential donors and recipients. Decision-making can be facilitated if these issues are considered prior to consulting with a donor's family and if an appropriate compassionate explanation of need for transplantation and basis of brain death diagnosis is provided based on a knowledge of underlying social constraints. Such steps can make the donation process smoother for both health care workers and the family.

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Public attitudes

One simple, albeit non-sensitive, way to assess social attitudes is to conduct surveys or questionnaires. The results of these surveys are most meaningful when they involve a large number of respondents, homogeneous groups, when they are repeated at intervals, and when subjects are interviewed as opposed to giving only written answers [1]. Obviously, the questions should be clear and easy to answer. One option is to make the questions multiple-choice so that the respondent need only check the appropriate reply. However, with this method, one alternative should always be blank in order to leave room for replies that might not have been considered by the authors of the questionnaire. The multiple-choice method also allows for easy analysis (quantitation and comparison) of the results.

Very few surveys have assessed societal attitudes towards organ transplantation, commercialization of transplantation, and brain death in Islamic countries. Those that have been published suggest that there is wide acceptance of renal transplantation, but that people have doubts and are suspicious about the concept of brain death, and fear that brain death may be wrongly diagnosed. There is also extreme aversion to any form of mutilation of the body in Islamic societies [2,3,4]. The research to date indicates that secondary school students have the most positive views on organ transplantation. These children have surprisingly strong awareness of the need for transplantation and what the process entails. All the studies from these countries show that people reject commercial transplantation for ethical and religious reasons [2,3,4].

Questionnaire investigations by the Saudi Center of Organ Transplantation that have surveyed doctors in intensive care units (ICUs), transplant centers, and transplant coordinators have consistently shown that these respondents believe societal habits and resistance accounts for more than 50% of donation refusals [5].

Basis for Fatwas (Aql versus Naql)

The importance of religion in Islamic countries is so great that it is difficult to distinguish religious and societal behavior. The reason for this is that Islam dictates everyday behavior in detail. The Quran instructs a person on such things as how to dress, how to put on shoes and how to eat, so essentially there is no distinct border between what is cultural and what is religious. When a Moslem is faced with a situation that must be acted on or responded to but the correct action/ response in line with Islam is unclear, he/she asks a religious scholar for an authoritative ruling on a point of Islamic law (a "fatwa"). By the same token, a government might ask for a fatwa before passing a controversial law.

Such details are relevant to transplantation because, in Islamic countries, fatwas must be passed before this practice is allowed and brainstem death is accepted. Today, most of these nations allow both living-related and cadaver-organ transplantation, but they vehemently reject commercial transplantation. Concerning the equating of brainstem death with cardiovascular death, a clear fatwa of approval was passed by Islamic scholars representing all Islamic countries in a meeting held in Amman, Jordan in 1986 [5].

A fatwa may state that the situation in question is permissible ("halal"), impermissible and sinful ("haram"), or improper but not haram ("makrouh"). Also, a basic tenet of Islam is that actions are considered halal unless proven otherwise. The primary source of reference for reaching a fatwa is the holy Quran. The next most valuable source is the "hadith," which describes the sayings and actions of the Prophet Mohammed. If neither of these contains a reference to the issue in question, the scholar looks for precedence in a book that portrays the actions of the prophet's companions ("sahabah"). Failing this, the scholar uses "ijtihad," meaning he passes his own opinion as a best guess based on intuition. For ijtihad, most conservative scholars use "naql" (following previous thoughts and ideas almost literally) whereas more open-minded scholars use "aql" (logic, commonsense). As one would expect, supporters of aql are more accepting of transplantation than supporters of naql. It is interesting to note that the famous Arab-Spanish scholar/Aristotelian philosopher Ibn Roshd (Averroes) was vilified and almost excommunicated because he stressed that aql is equally important to naql when reaching a fatwa. Another aspect of reaching a fatwa is the use of "qayas," or comparative inference.

Islamic scholars based their fatwa that permitted organ transplantation on the following considerations:

1. Altruism: Like other major religions, Islam advocates and encourages altruism. Organ donation is one of the clearest examples of altruism;
2. The concept that avoiding harm transcends attaining good;
3. The belief that human life is sublime, as expressed clearly in Surah Al-Maeda, the chapter of the Quran entitled "The Feast." "When one saves a life it is as one has saved all mankind";
4. Need is considered the same as necessity. Therefore the need for an organ equals a necessity;
5. Necessity permits the doing of forbidden things.

Specific Islam-related Considerations in Transplantation

Many factors influence the attitudes of people in Islamic societies towards organ transplantation. These are discussed below.

Donor Suicide Factor:

In Islamic countries, there is concern that the suicidal death of a donor can impact an organ recipient's well being. Like certain other religions, Islam considers suicide an abhorrent act. People who commit this act are considered non-believers and are doomed to go to Hell. It is therefore crucial that, when an organ is obtained from a body of a suicide victim, the recipient must be chosen carefully and should, under no circumstances, be informed of the cause of death of the donor. At our center, there was one very successful cardiac transplantation case in which the patient did well for 8 months but then somehow became aware that the donor died from suicide. Thereafter, she refused to take immunosuppressive therapy, went into acute catatonic depression, and developed acute rejection. Nothing could persuade her and no psychiatric intervention was successful at getting her to resume taking her medication. She died 1 month after she learned about her donor.

The Local Imam Factor:

There is no hierarchical structure among religious leaders in Islam. Therefore, a fatwa proclaimed by a person or group of people (see above) is not binding

to any given individual or group. This often causes problems in relation to transplantation. A health care professional or transplant coordinator may tell a relative of a potential organ donor that an official fatwa has been passed encouraging donation. That person will often seek the opinion of his or her local "imam," the trusted leader of the nearby mosque. This local imam may have a different view (fatwa) on transplantation.

Relationships Linked to Breast-Milk Feeding Factor:
Islamic beliefs related to breast-feeding are unique and interesting. Any woman who breast-feeds a child three to five times or more is considered to be the baby's mother, even if she is not the biological mother. Further, this woman's children are considered to be the breast-fed child's "siblings." Although they may not be blood-related, when these "breast-milk relatives" become adults, marriage between them is forbidden. Based on this belief system around breast-feeding, we also accept breast-milk relatives as "true relatives" for the purposes of donation. We consider this form of donation to be more than just emotionally driven, and view it as equivalent to living-related donation. We have been doing transplantations within these for the past 23 years, and noted excellent results very early on. Initially, we wondered if this act of "shared" breast-milk feeding endows some sort of tolerance among recipients of the same woman's milk. Today, we know that non-related donor transplantation is often associated with good graft survival.

Spousal Donation Factor:
The Quran clearly states that Allah (God) promised to "…endow them (i.e., a married couple) with 'moadah' (love and caring between them) and 'rahmah' (kindness to one another)." In line with this, spousal donation has always been fairly common practice in Moslem countries. In Saudi Arabia, we have been doing this for more than 20 years, and it is interesting to note that, contrary to what might be expected, more husbands donate to wives than vice versa [6].

Timing of Soul Departure Factor:
According to beliefs in Islamic societies, departure of the soul occurs concomitantly with or precedes death. Very often, the relatives of a brain-dead person link soul departure to absence of a heartbeat, and they therefore deduce that the soul has not departed since the heart is still beating. In reality (and this we must explain often), the Quran does clearly state, "the soul's destiny and status resides only with Allah, and humans have no knowledge thereof." It is usually very helpful to explain that, according to Islam, it is believed that the soul does not enter the body of a fetus until 3 months into pregnancy, yet the heart is already beating at that time. (As an aside, according to Islamic teaching, there is also no objection to obtaining stem cells from fetuses that are aborted early.) Conversely, the heart stops beating during open-heart surgery, yet we know that the soul has not departed and the person remains alive.

Fear of Disfigurement Factor:
The fear of having one's body disfigured is a real cause of anxiety in Moslem families. The physician must do everything possible to assure minimal disfigurement of a brain-dead donor's body and reassure the relatives accordingly.

Influence of the Extended Family Factor:
In Moslem societies, families tend to be close and maintain strong connections with extended family members. Adult members usually stay closely linked even after they marry and have their own children. Every adult member has his or her say in family matters, and opinions of senior members are held in particularly high regard. For example, a grandfather will often decide how his grandchildren will be educated, and even what their names will be. Thus, a single member of the extended family with high status may veto a decision for donation, even when the majority of members are in favor and the closest next of kin (i.e., a dead son's father) wants donation to proceed. With all these considerations of family members' opinions, it takes a long time to make a decision regarding organ donation after death. Even after a decision is made, there is always the possibility of reversal. Considering the connections explained above, to streamline the decision process, the best person to approach regarding potential organ donation is likely the "senior" family member as opposed to the closest next of kin.

Characteristics of the Transplant Coordinator Factor:
In Islamic countries, seniority (age), maleness, nationality and strong religious background are all important features of the person who talks to a family about

organ donation. In these societies, people tend to trust males more than females, and older males in particular. Currently, decisions about organ donation are largely based on religious belief, so there is much less chance of refusal if the team seeking consent has at least one member who is religious. Another major issue that causes difficulties is society's lack of confidence that there are clear criteria for diagnosing brain death. This is compounded by the fact that society as a whole does not trust the capabilities of doctors of a certain nationalities and most physicians in ICUs are of this nationality. In our experience, the chances of obtaining consent are much higher if the person who makes the brain-death diagnosis is a native of the family's country.

Parental Status and Influence Factor:
In Islamic teaching, submission and obedience to parents is paramount. One Quranic verse [7] states: "Thy Lord has decreed that ye shall not worship none but Him, and that ye be kind to parents. Whether one or both attain old age in thy life, say not to them a word of contempt, nor repel them but address them in terms of honor. And out of kindness, lower for them the wing of humility." Therefore, in Islamic societies it is more common to have sibling-to-sibling and offspring-to-parent living-related transplantation than transplantation from parent to offspring [6]. In contrast, the latter form predominates in Western countries. Parent-to-offspring donation accounted for only 11.2% of all transplantations, whereas sibling-to-sibling and offspring-to-parent donations occurred in 54% and 26.5% of cases, respectively [6]. We believe that this pattern reflects the exalted status of parents in Moslem societies.

Religious Importance of Womenfolk Relatives Factor:
Another interesting trend in Islamic society is that the men in a family are more likely to donate than the women. One study from Saudi Arabia revealed that male donors provide for 68.5% of living-related organ transplants, whereas female donors provide 31.5%. This societal habit probably has its root in Islamic teaching, as the Prophet said, "If anyone has three daughters or three sisters and treats them well, you shall enter paradise."

Rapid Burial Factor:
Islam clearly dictates that the dead should be buried as quickly as possible. The transplant physician will be asked how he/she can facilitate this, and the hospital should be set up to assist. The body should be released to the next of kin immediately after harvesting, and the transplant coordinator should assist with transport, ablution and other necessary rituals as much as possible.

Social/Tribal Pressure Factor:
This is an important factor for physicians, particularly transplant and ICU doctors. As mentioned above, the majority of ICU physicians in some Moslem countries are non-native, and are mistrusted by the public. These physicians, and many native ICU doctors, are often reluctant to diagnose brain death or seek consent for donation. The social background to this reluctance is that many Moslem nations include tribal communities, and "bearers of bad news" are shunned in these communities. In Saudi Arabia, there are documented cases in which members of the potential donor's tribe have occupied (using armed force) the ICU where the brain death and/or request for consent took place. There have also been occasions, fortunately rare, in which a surgeon who performed a failed living-related transplantation has been threatened and has required protection armed bodyguards for a period. These anecdotal events are dramatic, but it is important to emphasize that most responses to requests for donation in Islamic societies are polite and civilized, even in cases of refusal. During the early stage of development of transplantation in one Islamic country, a doctor was placed in detention for a week while an investigation was carried out. He had told the family of a brain-dead person that the only reason he would keep the ventilator on was to maintain the viability of the patient's organs in case they agreed to donate. The family made an official complaint to the authorities, who promptly ordered the doctor's detention.

Close Family Tie Factors:
There are countless emotional stories of living-related organ donation that illustrate family connectedness. In Islamic society, marriage extends beyond the joining of two people's destinies (lives). It means that two extended families become connected, and can even cement tribal ties in some instances. In the past, rulers and tribal sheikhs used marriage as a way to extend their realms and strengthen fighting forces. In light of

these connections, some Moslem countries allow living-related donation between members of families that are linked by marriage. One of the authors (FAS) once cared for a kidney transplant recipient who was dying from liver disease. When the patient's Saudi donor was told about this serious state of affairs, the donor was particularly keen to know how his donated kidney was doing. On hearing that it was functioning well, he expressed a gloriously happy smile, as if to say, "My donated kidney did not let my dying brother down." An Egyptian donor sobbed when he was refused as a donor to his son due to calculi in both his kidneys. A Pakistani donor's eyes flashed with happiness and elation when she was deemed fit to donate a kidney to her brother. She requested that we allow her to be the one to tell her brother the "good news."

Desire for Pregnancy Factor:

Pregnancy and the bearing of children, especially male children, have important social effects on women. When a woman becomes a mother, her standing in society is enhanced, both as an individual and as part of a married couple. The chances of being divorced, and the likelihood that the husband will marry another woman are also reduced. As the children, and particularly the males, become adults, get married and have children of their own, the mother's status in the family and in the community continues to rise. The connection to transplantation is that many women seek this operation not for the usual reasons, but out of a desire to improve fertility and become pregnant. Moreover, many transplant recipients push for pregnancy even against their physician's wishes. In many Moslem countries, the incidence of pregnancy post-transplantation is approximately 50-fold higher than in the West [8].

Annlies Factor:

Earlier this year, the first renal transplantations ever to be performed in Aden, Yemen were completed, and many societal lessons were learned from this experience. Five living-related transplantations were carried out in March 2003 as volunteer work done pro bono by physicians and other renal health care providers. The participating team was from many parts of the world (Yemen, Saudi Arabia, Syria, Lebanon, Poland, the UK, Austria and Canada). One member of the team was Dr. Annlies Fitzgerald, a clinical psychologist from Vienna who worked in the past as a dialysis and renal nurse and now has special interest in the psychodynamics and ethics of organ transplantation. She spent an enormous amount of time with the donors and recipients before and after the operation, talking, reassuring and generally calming them. The donors and recipients were all uneducated people with no previous experience or exposure to advanced medicine or foreigners. It was remarkable to witness the extremely close bonding Dr. Fitzgerald developed quite quickly with these individuals, even though the patients spoke another language and she was from a totally different background and culture. Lively communication took place across these so-called "barriers." By the second meeting, they were laughing together like close friends who had been reunited after a long period of separation. As a sign of real bonding and friendship, Dr. Fitzgerald received some valuable personal gifts from the patients, including photos of their children, and prayer mats and prayer beads that they possessed and used for many years. This experience revealed that, underneath apparent societal differences lies an unshakeable capacity for human bonding. It also shows the almost identical human response to situations such as organ transplantation, and illustrates that all patients who undergo this operation need psychological support, regardless of their background or culture.

Every person who works in the field of organ transplantation should have skills that allow them to bond with people. Organ donation and transplantation stir emotions, and it is vital to have the ability to connect with those involved, regardless of culture, background or language. This is important for patients and relatives, the latter in relation to attaining consent for donation.

The essence of this bonding is the ability to build security and confidence, to be very sensitive in contact with the other person, and to use all the resources for the moment and the situation. This connection comes first and foremost from the heart, from reflecting on one's own role in the process of transplantation and from learning the tools necessary to facilitate the communication process in a critical moment. Dr. Fitzgerald is teaching all this in the COPe-Program, a special training program for professional communications in highly emotional situations.

Doctors' Anxiety Factor:

A number of lessons were also learned from the first

cadaver-donor transplantation done in our country, and these can be extrapolated to other Islamic societies. The first-ever harvesting of a cadaveric kidney in Saudi Arabia was done by one of the authors (AAA) and another physician (Ketab Elotaibi, MD) [9]. This experience showed us that donation is more acceptable to people in Saudi society than we ever imagined. In this case, the donor's next of kin expressed his willingness to donate even before we finished making our request. The man realized the tension and anxiety we were feeling in asking about harvesting, and it was he who put us at ease. This particular experience also taught us that, in view of potential influences from the extended family (see above), it is often best to approach not the immediate next of kin but the family member who appears to be most sympathetic to the cause of donation.

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