

Factors influencing decisions on organ donation in brain death patients

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Abstract

Organ donation is an integral part of the health care system. Many patients who have had an accident or have undergone a progressive disease are in need of an organ transplant and if they do not receive the required organ they would die. It is important to know that the most important source of organ donation is the brain death patients. It is highly essential to determine the pivotal factors that have an effect on organ donation. The aim of this study was to determine factors influencing decisions on organ donation in brain death patients. This study was conducted in 2014 and was based on a literature review both in English and Persian databases. In addition, some relevant books were scrutinized. Overall, 2 categories were identified as factors associated with the acceptance of organ donation and factors associated with the refusal of organ donation. Based on the results obtained, these factors have an effect organ donation and policy makers and management authorities should consider these factors to increase the likelihood of organ donation.

Keywords: Organ donation, Brain death, Factors

Introduction

Successful organ donation gives a new life to patients with progressive and incurable diseases. The crisis of organ donation is depicted in media around the world on a regular basis (1). In fact, one of the most important challenges of today's healthcare system in Iran is the loss of thousands of lives in which some people are in need of organ transplantation (2). Currently, organ transplantation is one of the most effective options for those with an end-stage organ failure (3). The major sources of organ donation are brain death patients in the world (4). Due to the high rate of brain death patients, the body parts of these patients can be donated. This helps the lives of those who need organ transplantation and improves the quality of their lives too. On the other hand, this decreases the healthcare costs for these patients who need organ donation (2).

One of the reasons for the low number of donations from brain death patients is that the process of organ donation

from brain death patients puts the families of these patients under pressure to accept such donation. It should also be noted that social, educational, and, spiritual factors have an impact on this process and makes decisions difficult for the families (5). Shih et al (6) reported that, organ donation for the family members especially for Asian families, is a difficult and complex decision. Recently, more families agree with donation but there are many people who still oppose this action (7). As the first step in designing and planning interventions in order to increase the acceptance of organ donation, it is necessary to determine the influencing factors on organ donation. By identifying these factors, healthcare team, managers, and planners can help families in their decisions regarding their loved one's organ donation to go through this agonizing decision much easier. Therefore, the aim of this study was to determine the factors influencing decisions on organ donation in brain death patients.



Methods

This review was conducted by searching English databases (Cochran, PubMed, CINAHL) and Persian databases (SID, Magiran, Irandoc) in 2014. In addition, some relevant books, texts, and reports were examined by the researchers of this study as a desk review. Our search strategy included keywords such as organ donation, transplantation, and brain death. After considering the appropriateness of each article and books in terms of the study goals regarding the identification of the factors having an impact on organ donation, the identified articles were scrutinized and the key points for decisions on organ donation were extracted. For validity assessment and data abstraction, three authors (AB, MS, HR) screened the obtained titles and abstracts for eligibility. We excluded papers first on title, then abstract, and finally on full text. When studies seemed to meet eligibility criteria (or when information was insufficient to exclude them), we obtained the full text articles.

Results

As shown in Figure 1, the results of this study are presented in 2 main categories including factors that increase organ donation and factors associated with refusal of organ donation. Each of the 2 main categories has some subcat-

egories which are described in below.

1. Factors associated with the acceptance of organ donation

1.1. Humanitarian act

If brain death patients voluntarily donate their body parts to the people in need of organ transplantation, the resultant would be less death and dying and a new life would be given to these patients. Thus, organ donation is considered as a humanitarian action, an action of social contingencies, which is the basis of socio-ethical issues (1). In a study by Manuel et al (8) in 2010, they examined the experiences of organ donation families in the USA. The results showed that families considered organ donation as a positive experience and explained that their motive was to save the lives of patients who needed organs. They also expressed that this helped patients to continue their lives. In another study by Martinez et al (9) humanitarian tendencies were considered as one of the most effective factors on the decision of the families for donation. In a systematic review by Kurz et al (10), it was shown that altruism plays a pivotal role in decisions regarding organ donation in African Americans. It should also be noted that Montazeri et al (2) identified some humanitarian motivators such as altruism, giving an opportunity for

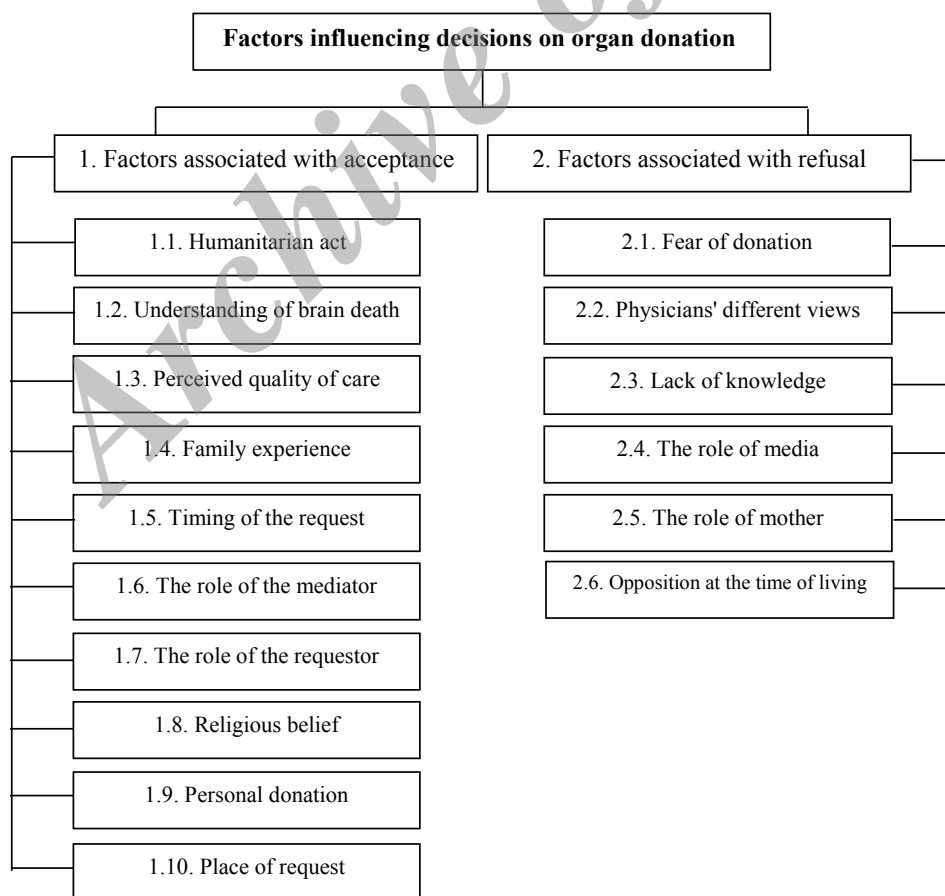


Figure 1. Factors influencing decisions on organ donation.

living by donating organs, and helping patients in need of organ donation in their study. These motivators had a salient effect on the decisions about organ donation. In a qualitative study regarding the experiences of organ donation families in 2006 in Australia, Wilson et al. found out that the main reasons for organ donation was saving the lives of patients in need of donation in order to help them have a better life (11). As can be seen from evidence, people consider organ and tissue donation as the greatest humanitarian act in giving life to another.

1. 2. Understanding of brain death

Depending on the level of knowledge and awareness about the concept of brain death, patients' families have different attitudes regarding organ donation. Decisions on organ donation are directly related to the families based on their voluntary action and if they accept the death of their loved ones. This can be facilitated if they observe the abnormal vital signs in their patients. This plays a role in their belief to accept the brain death in order to make decisions and give consent for donation. Additionally, the observation of critical medical tests can be considered as another factor that simplifies decision-making (2). In a study by Sque et al (12), observing visible signs of brain death patients had an important role in dealing with the request of organ donation for families. It seems that for some families, their background and previous knowledge is the reason for voluntary decision regarding donation. If they have an appropriate understanding of brain death, then the resultant is the facilitation of decisions. Regarding this matter, studies highlight that if families accept the brain death, they will agree with organ donation (2,9). Similarly, Zohour et al (3) stated that 93% of the people who considered brain death as irreversible could easily accept organ donation. Other studies also show that knowledge and attitude are the effective factors on decisions regarding organ donation (10,14).

1. 3. Perceived quality of care

The quality of care provided from the healthcare team during the hospital stay has a great impact on the families' decisions regarding organ donation (15). If families receive the appropriate care and companionship from the healthcare team, they can better accept organ donation. In addition, if the healthcare team assists them in gaining information about any unknown matters and provide the best quality of care, the donation process would be facilitated (16). It is important to know that implementing educational programs to increase the knowledge of brain death and donation for healthcare team is of utmost importance as these programs would instill positive attitudes and have an impact on their behaviors. It should also be noted that these programs are presented to emergency departments and intensive care unit personnel who directly deal with brain death patients as on the job training courses.

Obviously, these efforts will instill the positive attitudes towards organ donation (17). Thus, perceived quality of care during the hospital stay has a significant impact on consent rates. Conversely, a negative perception of care results in a decreased rate of consent.

1. 4. Family experiences

Experiences such as previous exposure to individuals who needed organ donation, the death of a person in need of donation, and familiarity with the physical condition of those in need of organs, have a positive impact on the decision for organ donation (2). This was emphasized in the study of Burr. in which the experiences of participants were considered as an important theme (14). Rice and Tamburlin showed that those people who had a relative in the waiting list to receive organ donation were more susceptible to accept donation in comparison to those who did not have this experience. In a similar vein, when a member of a family has a tendency for donation, other members have the same willingness (19).

1. 5. Timing of the request

The time of request plays a key role for organ donation. This means that an appropriate time must be considered and given to the family to accept the death of their loved ones before organ donation (20,21). In the study of Montazeri et al (2) it was shown that due to a period of time lag between hospital admission and the death, they could more easily deal with donating the body parts of their loved ones. It seems that there is an improved rate of consent when there is a time lag between notification and acceptance of brain stem death and request for donation. Niles and Mattice (21) studied the timing in the approach process and determined that the consent rate was similar regardless of whether families were approached either before (62%) or after (57%) death but much lower when donation was mentioned at the time of the death notification (25%). Giving families enough time to make a decision was also considered important. Many families (60%) who had a plenty of time for discussion consented to donation, while only 27% of those who thought they had insufficient time for discussion did so (22).

1. 6. The role of the mediator

Another important factor regarding the decision of families for organ donation is the role of mediators in the organ donation process. Mediators are physicians and clergymen. They play the role of a facilitator in order to find a remedy for the ethical problems of the families facing organ donation. Most families refer to their reliable physician after the diagnosis of brain death. The approach taken by these mediators in order to confirm or reject the brain death of a patient has a contributing role in the final decision of the family. It appears that if these mediators do not confirm the brain death of a patient, then the resultant

is less approved rate of consent for donation. Conversely, confirming the brain death and the failure of recovery for the patient by physician as a mediator, facilitates the decision making process for organ donation (2).

1.7. The role of the requester

Since the detail of a brain death is circulated by the requesting doctor not the doctor who provides the medical care, his/her role becomes of salient importance in order to gain the trust of the family for organ donation. In this regard, his/her interaction with families, the ability to convince the families, and providing correct information is by no means crucial (2). The results of the studies show that the role of the requesting doctor on the decision making process is important and a skillful requestor can facilitate the decision of families regarding organ donation (23,24). As the expertise of the person making the request is important, Shafer et al (25) conducted a study in a large 500 bed public trauma hospital. In this hospital two coordinators were hired, one white and one black, to work exclusively in the hospital, closely managing and coordinating the consent process. After implementation of the program and the use of race specific requestors, there was a 64% increase in the consent rate and an overall increase of 94% in the number of organ donors.

1.8. Religious Belief

There is a variation in the rate of consent regarding organ donation when it comes to issues such as customs, traditions, religion, and cultural beliefs. Studies show that the impact of cultural and religious beliefs is one of the key factors in the decision making process (2,9,10). Montazeri et al (2) highlighted that the rate of consent differs based on these items: considering death as inevitable, having belief in fate, being alive after death, and the continued existence after dying. Randhawa (26) expressed that culture and religion play an important role in organ donation and religious decree is important for many Asians especially Muslims. In a study by Rithalia et al (27), it was shown that catholic people have a more favorable attitude towards organ donation as the religion officially recognizes organ transplantation as a "service of life".

1.9. Personal donation

In the study of Martinez et al (9), among the decisive variables, characteristics of the deceased were considered as a key factor in the satisfaction process. In fact, one of the most predictive factors in families' decisions regarding donation is related to the willingness of the deceased before his/her death to agree with donation. Heinrich et al (28) highlighted that the patient's previously expressed interest and his/her alacrity in signing up for organ donation would implicitly have an impact on the motivations of families for organ donation. In this regard, the consent rate would be 95%. Based on the results of Broumand's study, more than 80% of families agree upon donation if

they understand that their loved one has agreed upon such donation in advance (3). Therefore, the consent of the deceased as well as the family's satisfaction is important in this case.

1.10. Place of request

Setting in which the request is made has an impact on the decisions regarding organ donation. It seems that a private location in order to have a discussion about organ donation improves consent rates. Evidence shows that consent rates for requests made in settings that provided little privacy were 45% and 30% compared with consent rates of 56% and 52% in more private settings (29,30).

2. Factors associated with the refusal of organ donation

2.1. Fear of donation

Fear of donation, the chances of recovery, and rejection by others were some factors that were highlighted in the study of Hosseinrezaei et al (16). Stevens (31) identified similar beliefs associated with donation, including the fear of not being dead when donation takes place, and the fear of feeling pain after death. Another study stated that in terms of signing an organ donor card, nondonors had a high fear of death and had a sense of physical anxiety, but donors exhibited an acceptance of death and reported a high level of perceived self-efficacy with regard to signing a card (32).

2.2. Physicians' different views

Studies show that different viewpoints of doctors put families in a perplexed situation in order to make a firm decision regarding organ donation. It seems that due to the lack of precision in defining brain death by some practitioners and having diverse views about it, families would hold a negative view and this decreases the rate of organ consent (33). Some of the families who rejected organ donation mentioned that the explanations of the physicians were inadequate and not convincing enough to help them in their decisions (2).

2.3. Lack of knowledge

Families think that as the heart pulse beats and the person is still alive and the body parts work, they should not be discouraged and hope for the survival of their loved ones. Therefore, they resist against organ donation strongly (7). Families lack of knowledge on the concept of brain death plays a part in this regard and it is more prominent when it comes to the times when the patient is in coma or in a vegetative state (7). Thus, it appears that brain death is often confused with a vegetative state or coma. Montazeri et al point to the false thought of recovery due to the previous experience of coma recovery (2). Another study showed that the attitude of most families is not correct about brain death and they think that brain death is reversible (3,13). Other studies also showed that lack of information plays a part regarding the refusal of donation (4,29,35,36).

2.4. The role of media

Media has a role by imposing a feeling of doubtfulness to death and instilling this idea that a brain death patient can be recovered. In this regard, some of the families may decide not to accept donation. It seems that films with the contents of buying and selling organs, and depicting a chance for patients to come back to this world alter the decisions of families to accept donation (2). Morgan et al (37) showed that family members received significant information about organ donation from media and unfortunately most of this information was negative about donation. In addition, the results of their study presented that there are some barriers in organ donation which are spread by displaying negative media about organ donation. This matter was also highlighted by Maloney and Walker (36). They expressed that media can increase the doubtfulness about organ donation in families by the kinds of films they show to their audiences.

2.5. The role of mother

In almost all families, fathers pay attention to the mother's opinion about donation. Most of mothers who were willing about donation finally persuaded their husbands to accept donation. Conversely, mothers who were not agreeable with organ donation did not accept donation even though their husbands were agreeable (2).

2.6. Opposition at the time of living

Rosel et al (38) expressed that if the family members of the deceased know that the person disagreed with donation, they would not accept donation. In the study of Sque et al (12) the most important reasons for families' disagreement about donation was the understanding that their loved ones opposed organ donation.

Discussion

The main aim of this study was to determine the factors influencing decisions on organ donation in brain death patients. Results showed that there are several factors which play a part in the acceptance and refusal of organ donation. Humanistic and altruistic behaviors are considered as the most effective factors on organ donation. One of the other effective factors regarding donation is the acceptance of brain death. As the acceptance of brain death gives room to donation, we recommend that the healthcare team ensures a correct understanding of brain death for families upon donation. To achieve this goal, clear and understandable information should be given to families. It is recommended that practitioners who are involved in the process of organ donation provide a suitable context for accepting the fact of brain death for families. Secondly, they must consider the experiences and impressions of families about this complicated situation and try to solve the contradictions and ambiguities. The healthcare team has to follow the clinical procedures and all actions regarding the brain death. This signifies that the healthcare

team uses the whole possible efforts to remove doubts and worries about any kind of decisions. It is of great importance that the healthcare team takes heed to where they want to make the request of donation as a place with privacy increases the rate of consent. The requestor must be a person who has all the necessary information about the brain death. This person must also have good communication skills to satisfy the families and answer their questions in the best way possible to avert any doubts. This person should also be familiar with the factors that cause organ donation consent and refusal in order to be able to use them in the best way. On the other hand, matters such as fear of donation, different views of physicians, lack of knowledge, the role of the media and mothers as well as opposition of the patient at the time of living should be taken into account. Generally, we believe that public education is necessary to familiarize people with brain death. It is also vital to distinguish the difference between brain death and other similar medical conditions. This facilitates the decision making process and instills the right attitudes in people involved in it. Our findings also show that many people would be reluctant about organ donation as they are impressed by related movies and films. As the media has a profound effect on decisions about organ donation, we recommend that special programs about brain death and organ donation be made. For instance, media can depict the differences between coma, vegetative, and brain death states and provides information about an irreversible brain death. It is important that all members of society announce their opinions about organ donation. Even, we suggest role models with high prestige to make public announcement about donation. Finally, it would be great if related organizations in charge of organ donation consider some formalities to thank the families of brain death patients who decided to donate. Their appreciation can be an incentive for other families and society in general.

Conclusion

As our study has classified the influential factors associated with organ donation acceptance and refusal, policy makers, managers, and the organizations in charge can use them in their planning. They ought to consider these factors in order to increase the likelihood of organ donation. The results of this study can also be used in order to design a special instrument to evaluate and determine the significance of these factors in other studies. The last but not least, our findings can be applied in the training of medical students, physicians, and the healthcare staff.

Ethical issues

Not applicable.

Authors' contributions

All authors equally contributed to the writing and revision of this paper.

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