

Family Members Experiences Related to Organ Donation of their Brain Death Patient

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Abstract: Organ transplantation from brain dead patients in Sri Lanka has become a critical medical intervention since the availability of organs has fallen behind the requirement. Nonetheless, the difficulty in obtaining the consent by the family members still exists as it was. This study aimed to describe the family members' experiences related to organ donation of their brain death patients in Neuro - Surgical Intensive Care Unit in National Hospital of Sri Lanka. Ten immediate family members who have provided their consent to proceed with an organ donation of their loved ones were selected purposively. The interviewing was held at the hospital premises. This was conducted as a phenomenological study. Data collection was performed with semi-structured interviews using a theme guide from March to June 2019. Thematic analysis was used for data analysis. Ethical approval was obtained from the National Hospital of Sri Lanka. Three themes that emerged from the transcribed interviews were: decision conflict, respecting the donor and acceptance of the unexpected death. Stressful decision making, family involvement and internal dissonance were the sub-themes emerged from decision conflict. Further, religious beliefs, honouring the donors' wishes, saving recipient life, letting the donor live on and comforting the grief were the sub-themes derived from respecting the donor. Dedication of health care professionals, the ambiguity of brain death and awareness derived from the last theme. The study revealed that the overall attitudes towards organ donation of a brain death patient exist to a slight negative bias

among Sri Lankan society. Hence it is recommended to have public educational interventions to educate the society regarding organ donation.

Keywords: Brain death, Organ donation, Family Members, Experience

Introduction:

The concept of brain death can be defined as the irreversible end of all brain and brain stem activities. Moreover the concept of brain death varies with other acute brain disorders like the vegetative state and coma (Yousefi et al, 2012). Due to the existing cultural and religious diversity in the world, different imaginations are embedded among people regarding brain death patients. Further their experiences were also affecting for their attitudes regarding brain death (Groot et al, 2012). The concept of brain death have paved pathways in a new dimension for the organ donation process. Instructions for the organ transplantation is also appearing in WHO guiding principles on human cell, tissue and organ transplantation, 2010.

Considering the organ donation in the international context, the rates on organ donation in India was identified as 0.26 per million, United States, it was 25.6 per million, 18.3 per million in United Kingdom and 32 per million in Spain (Wig et al, 2003). Considering the Asian context, it is clear that the family members of the brain death patients with other intact organs have to face an ethical dilemma. Providing the consent or taking the decision to donate organs were mentioned as the most difficult and complicated issue).

Furthermore factors like bodily disfigurement of the dead patient, failure of the families to understand the concept of brain death have highly influenced in decision making (Anker, A., 2010). Global statistics have confirmed that only 10% of the global needs of the organ transplantation is met (Matesanze et al, 2017). Each day around 60 patients all over the world were getting an organ transplantation. Nevertheless 13 patients die with unavailability of organs all over the world (Sulania et al, 2016)

As a developing country still Sri Lanka has many people who are in the waiting list for an organ transplantation. Yet the donated organs were less than the requirement. Most of the patients who are brain death are buried in Sri Lanka due to the unwillingness of the family members to donate. Therefore this was conducted in the aim of exploring the family members' experience who are directly involving with the organ donation of their brain death patients in Neuro- Surgical Intensive Care Units in National Hospital of Sri Lanka. Specific objectives of the study were, to identify psychological experiences of the family members related to the organ donation of their brain death patients, to explore socio-cultural experiences of the family members related to the organ donation of their brain death patients and to describe institutional experiences of the family members related to the organ donation of their brain death patients in Neuro- Surgical Intensive Care Units in National Hospital of Sri Lanka.

Methodology:

This was a qualitative study with descriptive phenomenological approach. The study was conducted in the premises of the National Hospital of Sri Lanka (NHSL). Study participants were the family members of brain death patients who were admitted to Neuro – Surgical Intensive Care Units. They were in the age group of 30 -67. There are five Neuro Trauma Intensive Care Units in the NHSL

including an emergency treatment unit. Ten immediate family members from ten families were selected purposively joined the study to provide face to face semi structured in depth interviews. The inclusion criteria for the participants was being an immediate family member who has signed a consent form for an organ donation. Ethical approval for the study was granted from the ethics review committee of the NHSL.

Written invitations were provided for the participants and obtained the informed consent to conduct the study. Semi-structured in-depth interviews were conducted with the ten participants for a half an hour to one-hour length depending on the participant's demand. The participant's confidentiality was maintained throughout the study by using a specific code to identify the participant. An interview guide developed by exploring the literature provided the main structure for the interviewing process. The theme guide was validated with the expert guidance and opinion. Interviews were initiated with the question "can you disclose about yourself". Eventually the investigators have asked about the experiences of the family members. Interviews were ended when the investigators were satisfied and believed that all the necessary information were gathered and the data were saturated. All the recorded interviews were transcribed and primary codes were derived. Then the subthemes and themes were derived according to the thematic analysis. The rigor of the study was maintained by the investigators by consulting the supervisors and the subject experts.

Findings:

Three main themes and eleven sub themes were generated with the data analysis. Main findings were represented in the table 1. Three main themes emerged were the decision conflict, respecting the donor and the acceptance of the unexpected death.

The theme of ‘decision conflict’ explored the stressful decision making, family involvement and internal dissonance. Stressful decision making expressed by the family members are in a shocked and panicking behaviour. They are expecting a miracle to happen and save the patient.

“I saw my sister was sleeping on the bed. She breathe well with the help of a machines. First I can’t believe that her brain was not working. (Silence) I thought she was having a comfortable sleep there” (Participant A)

Family involvement plays a major role in attempting to do an organ donation, there the immediate kin of the donor was not the only person to take decisions but his/her other relatives involve too. Cooperativeness and the understanding is a much more convenient in this regard.

“Organ donation is such an important issue. During our gathering we were used to spoke about such topics. We donated our father’s eyes also when he was died. I also spoke to my children about my wishes. My other two sisters and their children also accepted the decision without any hesitation. One of our daughter is married to a doctor. As a health care person his involvement made the family decision more comfortable.” (Participant B)

Most of the family members experience uncertainty and dissonance after making the final decision, some of the families who have agreed to donate their loved one’s organs suffered from uncertainty and dissonance regarding the organ donation process. Some internal conflicts have also emerged on the confirmation of the death as well. They think that their relative physically appeared alive and normal since they don’t have any visible injuries.

“Sometimes I thought that I should have kept him. May be he would have recovered from the coma. Sometime I asked myself if I was on the wrong side..... (Sigh).”(Participant C)

Table 1: Family members’ experiences related to organ donation of their brain death patient

Themes	Sub Themes
Decision Conflict	Stressful Decision Making, Family Involvement Internal Dissonance
Respecting the Donor	Religious Beliefs Honoring the Donors’ wishes Saving Recipient’s Life Letting the Donor live on Comforting the Grief
Acceptance of Unexpected Death	Dedication of Hospital Staff Ambiguity of Brain Death Awareness

Respecting the donor has derived five sub themes as, religious beliefs, honoring the donor’s wishes, saving recipient’s life, letting the donor live on and comforting the grief. Religious beliefs are one of the main concerns that are embedded among the family members. Most of them believed that donation will help the dead person in their afterlife.

“My sister is young. There is no meaning to just bury her body in vain. By giving her organ to another one can survive another life. Because of this she will be merited. Not only her, we too got a chance to involve in a donation.”(Participant A)

Honouring the donors’ wishes help in making the relations to conclude about the act of donation.

“My husband had a living will that in the case of his death. He wanted to donate his body.....then we agreed to donate his organ according to his will to honour him.”(Participant G)

Saving recipient’s life came up with the relative’s perceptions on improving the survival and quality of life in patients regarding a transplant and therefore participants appeared to believe that the consent for the donation should be given without expecting anything in return.

“Even though we don’t know the person who received the organs, it is very pleasure to think

that we helped to save another person's life."(Participant G)

Letting the donor live on provide the idea that the family members believe their loved one will be living on another person's body. So that it provides them the idea that the patient is no longer dead.

"I know that my husband's organ alive on somebody. I'm happy to think about that. Even though I was alone he gave life to another one. I think that I should remind this at three month Dana Ceremony." (participant J)

Comforting the grief in the sense of relieving from the thought of separation from the family. They think donation will make them a factor to celebrate in a good manner.

"We wish not to have unexpected death after a while. We made up our minds by giving his organ". (Participant I)

The theme 'accepting the unexpected death' has derived three subthemes as dedication of the hospital staff, ambiguity of brain death and awareness. Dedication of the hospital staff was derived due to the immense dedication that is being provided by the staff of the hospital, specially the intensive care units. They try their best to save the lives yet at last they failed.

"Doctors and nurses do everything to save my son. I don't know what to do. They do everything to my son. There's nothing I can do. I only trust about the medical team. We saw how much they try to save my son. But at last we all failed. (crying.....)." (Participant F)

Ambiguity of brain death signifies that the most of the family members were very unlikely knowing the terms and conditions related to brain death. They were so frustrated with this new information. All the terms are a lot new for them.

"I never got to know about brain death. I was confused how other body parts live in a brain death person."(Participant C)

Awareness explains the brain death and organ donation is a new concept to the Sri Lankan society. Since then there is no well-planned public awareness program to update the public. As well as normally Sri Lankans are not motivated enough to see medical information as a habit. So giving adequate information is a key role in organ donation process. Most of the participants had positive responses about the information from health professionals.

"Doctors explained me that even though my father's brain was death his organs work well. The doctor calmly explained the situation in detailed. After that we gave consent." (Participant C)

Discussion:

The study identified both positive and negative experiences of family members regarding organ donation of their brain death patient. Several Themes that were based on lived experiences of the participants were emerged with the organ donation process of the brain death patient. The discussion highlights the importance of the study and the findings of the study that may be benefitted in filling the existing gap in the field.

Psychological experiences of family members regarding organ donation

Stressful decision making is the most significant finding of this study. It is because most of the brain deaths are unexpected ones and the relatives feel sense of shock and panic. Some relations think that the patient's condition will reverse by miracle. This is consistent with a study conducted in China where it is described that disbelief, anxiety and acute psychological stress have been experienced in most of the families when faced with a brain death member (Wong & Chan, 2007).

Study revealed that the positive attitudes and cooperative involvement of the family members help to get concrete decisions. An Australian study findings also suggest that

existing, conflicting views and tensions ended up with anxiety and once the family member is over powered by another member make them reluctant to take decisions (Ralph et al, 2013). Moreover the internal dissonance directly affecting the decision making process. Healthy appearance of the body of the patient other than the severe injuries hidden increases the hope of recovery of the patient. According an Iranian study it is revealed that the more important the family role the patient plays, more the expectation of the recovery of the patient (Yousefi et al, 2012)

Socio cultural experiences of family members regarding organ donation

The current study revealed that religious beliefs play a key role in the decision making. Findings of an Iranian study stated that the chance of donation increases by the increasing one score in the domain religious beliefs (Ahmadian et al, 2009). Moreover another study revealed donating families are highly religious. Family members of these families express that donating is saving life of others in need. Furthermore and Australian study revealed that the diseased donor would be rewarded in their afterlife for fulfilling the religious teachings. It is seen that families tend to donate organs to save others' lives and helping them in the necessity. (Wilson et al, 2006)

Moreover honouring the donor's decision was very much important in organ donation. This finding was consistent with an Australian study, where the family members were confident about the patient's decision that makes them comfortable with donating. (Ralph et al, 2013). Further this allows the donor live on which was also confirmed by the Australian study where they have stated, donating the organ will let them live on another person body. This makes them to release the grievance come with the complete departure from the family as well (Ralph et al, 2013).

Institutional experiences of family member regarding organ donation

It is clear that the awareness provided on organ donation support the procedure, further this was also confirmed with Australian study where increasing the awareness of the family would be benefiting on late support in donation of the organs. Ambiguity of brain death happens due to the lack of knowledge on brain death on family members. The same concept evolved since participants request more comprehensive information on brain injuries and how they are medically confirmed (Ralph et al, 2013).

Conclusion

Beliefs and experiences revealed by the participants along with the ambiguity on brain death and organ donation is clearly emerged through the interviewing process. Family members of the brain death patients would be much benefited if much information about brain death identification is disclosed. This might help in improving the rate of organ donation currently existing in Sri Lanka.

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