**The Nurse's Role in the Decision Making intransplanted Kidney Donation: A qualitative research**

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Abstract

The decision to donate an organ, particularly kidney donation is very challenging and is influenced by various factors. Nurses have a major role as a facilitator in decision making.A qualitative design using a content analysis approach was used to collect and analyze data.Participants(n=17) were six nurse consultants, two physicians, three kidney donors and six family members of patients with brain death selected using a purposive sample method. A total of 26 semi-structured interviews were conducted. Five themes were created regarding the nurse's role in the individual and family decisions making for kidney donation. Themes included counseling, empathy, mediation, motivation, and acceptance of kidney donation.Nurses in roles such as counseling, meditation and empathy can facilitate individual and family decision making in order to donate a kidney. It is recommended that nurses understanding the situation and interaction with individual and family provide motivation to accept kidney donation.

**Keywords:** Nurse, decision making, kidney transplantation, organ donation, qualitative study

**Introduction**

End stage renal disease (ESRD) is a chronic and progressive deterioration in renal function in which the body fails in the ability to maintain metabolic, fluid, and electrolyte balance (1). One of the alternative treatments for patients with advanced kidney failure is kidney transplantation.Compared to dialysis, kidney transplantation increased longevity and quality of life in patients with end stage renal failure (2-3).The transplanted kidney donor could be dead or alive (4). Research has shown that the survival rate and quality of life in patients with a cadaveric transplanted kidney is more than those who received a kidney from a living donor (5). However, the waiting time to receive a cadaveric transplanted kidney is more than living donors (6-7).The reason could be lack of enough cadaveric kidney donation and brain death patients (8).Over the past two decades, the need for organ donation had a 200 percent rise (9). Statistics show that every month more than 3,000 people will be added to the waiting list for Kidney transplantation.From which 12 people have lost their lives in each day. Therefore, about 4270 patients waiting for Kidney transplantation lost their lives by 2014 (10). Despite many years of organ transplantation law in Iran, it is not welcomed yet. In fact, most of the population still do not have a positive attitude towards organ donation (11). Statistics show that about 20 thousand people are on the waiting list for Kidney transplantation in Iran; the majority of them are patients in need of kidney transplantation.Every year about 27000 living people worldwide donate their kidneys (12). Annually 2500 Kidney transplantations are performed in Iran, two-thirds of them are transplanted from living donors and recipients and one-third belong to the patients with brain death (13). Studies have shown that Kidney transplantation from living donors are more than a deceased donor (14-15).While each year in Iran 15000 brain death occurs as a result of car accidents, but only about 10 percent of the families accept organ donation. The organs of these cadavers could be used to improve the quality of life and reduce the cost of treatment and care of patients in need of organ transplantation (16). Studies have shown that family dissatisfaction is one of the key factors in the kidney donation crisis (17-18). Globally, the organ donation process depends on the families’ decision which in turn is influenced by several factors (19). Essential tips to improve the quality of care and contribute to the decision of the individual and the family is the professional relationship between nurses, patients, patient relatives and other members of the health care team (20).

As nurses communicate with the patient and their family members, they can have a significant impact on the individual and the family`s decision to donate a kidney. Therefore, this qualitative study could be helpful to show important details about the role of nurses in individuals and families’ decision-making to donate a kidney.

**Methods:**

Objective

This study aimed to explore the nurse's role in the individual and family decision makingin transplanted kidney donation.

Research design

A qualitative design using a conventional content analysis approach was used to collect and analyze data.

Participants and setting

A purposeful sample of 17 participant's(six nurse consultants, two physicians, three kidney donors and six family members of patients with brain death )was drawn from Ahvaz Jundishapur University of Medical Sciences and Kurdistan University of Medical Sciences , Iran.

Data collection

Semi-structured interviews were held for data gathering. Compared with quantitative data gathering methods, interviews provide deeper understanding of the intended phenomenon (21). Interviews were begun by asking questions such as, ‘What is your experience in helping an individual or family for organ donation? Besides, probing questions were asked for obtaining detailed information and adding to the depth of the interviews. At the end of each interview, the interviewee was asked to add any other points which had not been addressed during the interview. Data collection was terminated once data saturation was achieved and no new category was extracted from the collected data (22). Interviews were held individually in an interview room located in hospital. All interviews were recorded through a digital sound recorder and were immediately transcribed verbatim. The length of the interviews ranged from 30 to 90 minutes.

Data analysis

Data analysis was performed by employing the Morse and Field’s qualitative content analysis approach (23) and simultaneously with data gathering. Accordingly, each interview was analyzed before holding the next one. Immediately after conducting each interview, a verbatim transcript was made from its content. Then, each transcript was read several times in order to immerse in the data and achieve a general feeling about them. Thereafter, meaning units were extracted from the transcripts. Interview transcripts were read line by line and were coded accordingly. Codes with similar meanings were grouped into sub-categories. Sub-categories were also categorized according to their similarities and differences. Finally, the main themes were extracted and the process of data analysis finished.

Rigour

To ensure credibility of the data, data integration such as viewing manuscripts and recordings, reviewing data, nonstop supervision, allocating enough time for data collection, and good communication with participants were used. To confirm the accuracy of the data, implemented handwritten and extracted code phrases were reviewed by the participants (member check) as well as two research partners (peer check) and different views were summarized in a joint meeting.Then, an external researcher and expert familiar with the qualitative research were used as an observer.The readings were approved according to the same understanding of the findings. For data dependency, the interview recordings and manuscripts were stored for two years after the end of the study, so participants and observers had access to them.For the generalizability of the data, sampling was conducted with a maximum variation in participants and the environment.

**Ethical Considerations**

This study was approved in the ethics committee of the Ahvaz Jundishapour University of Medical Sciences, and Kurdistan University of Medical Sciences, Iran. Ethical considerations were considered in accordance with the Helsinki Declaration. The aim of the study was explained to all participants and they were informed that participation in the study was voluntary. We also ensured them of the anonymity of interview transcripts and the confidentiality of their data. Informed consent was obtained from them for recording the interviews and publishing their experiences.

**Results**

Data analysis led to extraction of 820 primary codes, 10 categories and 5 themes.These themes reflect the role of the nurse in the individual and family's decision to donate a kidney.Themes were counseling, empathy, mediation, motivation, and acceptance of kidney donation.

**Counseling**

This theme was extracted from the two individual counseling and family counseling categories; for individuals and families’ decision to donate the kidney voluntarily. In relation to individual counseling, some nurses and doctors in the intensive care unit had a negative attitude to organ donation, so nurses as advisor tried to reform them.

“As a nurse consultant for organ donation, when I went to ICU, I noticed some of the nurses and aid workers did not believe in organ donation which had a negative impact on family decisions.We made a number of counseling sessions to change their attitudes "(nurse Consultant 1).

People who applied for kidney transplantation did not believe in donating a kidney from the cadaver. They were identified by a nurse consultant at the department of dialysis and organ transplant unit and were given free counseling sessions.

"I was dialyzed for five years, which was quite boring.Finally, I decided to buy a transplanted kidney.One day, a nurse in the dialysis unit spoke to me about receiving the kidney from a brain dead patient.I was rejected first; but my attitude changed when several counseling sessions were carried out.Thanks God now that I use a kidney from a brain dead patient "(recipient of kidney 1).

Another nurse role as a consultant was providing family counseling at a time when she was not able to make a decision to receive transplanted kidney from a cadaver.

"As the father of a brain dead patient, I was continuously blamed by my other children for cutting their brother's body into pieces.God bless nurse, who convinced them finally after several counseling sessions.My son’s organs, including his kidneys are now in other bodies that need them". (Father of brain death patient)

“In my counseling sessions with families who were in need of a kidney transplant, I explained to them that, according to the evidence such as figures extracted from articles and kidney transplant centers, it is proven that life of people who had a kidney transplant from a deceased donor is longer than those who received a kidney from a living donor.This matter caused several families to buy transplanted kidney, preferably from a cadaver”(Nurse Consultant 2).

**Empathy**

This theme was extracted from the two other categories; mutual understanding and continued support of the individual and the families.Families with brain-dead patient have experienced various reactions ranging from denial, resistance and, ultimately, depression and acceptance of the reality.In fact, some nurses understanding the mourning stageswere consulting familiesand by accepting those in each of these stages prepared them to accept the reality.

"When I saw that the mother is not ready to accept the brain death of her child,we calmed her.After several days and tolerance she accepts that her son was brain dead.After this stage we talked to her about organ donation which was very effective. "(Nurse Consultant 3)

Nurses, in fact, with continued support from the donor or recipient of kidney families play an important role in the decision making to donate or receive a kidney transplant from a brain dead patient or cadaver.

"Let me thank Ms. Mohammadi (nurse), she was with us and gave us consolation all time long during my son’s stay in the hospital. Even after organ donation she participated in the funeral ceremony and made a link with my family" (mother of a brain dead child).

"When I went to organ transplant unit to receive a transplanted kidney, I had no money to buy any. But, Ms.... (Nurse) With her continuous support booked me on the list to receive donated kidney." (Seeking kidney patient)

**Mediation**

This theme was extracted from two categories of nurse mediation between families and physician and nurse mediation between donor families and recipients of transplanted kidney families.The nurses as a bridge connects different people, ~~including~~; physicians, families, kidney donors, and the recipient~~’s~~.

”When we talked to family members of organ donors who had previously been consulted by trained nurses, they accepted us easily.Nurses can be a good bridge between us and the families who have to decide organ donation.” (Physician 1)

Another important role of nurses was communicating between the donors and the family members of the recipient.In these circumstances, nurses as mediators were talking about their expectations and demands of families and a relative agreement was established among them.

**Motivation in the Individual and Family Members**

This theme was from two categories, to motivate for kidney donation and motivation to accept a donated kidney in spiritual, financial and social dimensions.In order to create a spiritual motivation, various activities were guided and managed by the nurses.

"People who sent their beloved ones with informed consent to the operating room for organ donation were invited to talk to other families with brain-dead patient about their own experience. It was important to create a sense of philanthropy and motivate them spiritually ".

Another nurse's role in creating motivation was to involve families in grassroots organizations, improving cultural backgrounds and setting up virtual sites in the community.

“In the organ donation unit we prepared a list of candidates for organ donation. In forums, meetings and conferences donors were introduced as a hero. "(Nurse Consultant 4)

Creating financial motivation for kidney donation was another way that the nurses were sometimes used. This type of motivation was often used for poor and low-income families.

“Because of financial problem, father of a brain dead patient did not agree to make organ donation. The hospital manger assisted me to free all transfer and funeral costs." (Nurse Consultant 5)

**Acceptance of Kidney Donation**

The outcome of the nursing intervention in individual and family`s decision making was to accept to pay or receive a donated kidney.This was important in families with brain death patients. Since the time of brain death, family members had different reactions such as denial, resistance, aggression, and acceptance.Nurses as a consultant identify this process to come into acceptance.

“The mother of a child who believed her child was not brain dead was aggressive and blamed nurses and physician for the death of her child. However, after consultation with nurses and physicians she proposed us to donate the organs of her child "(mother of the deceased child)

Individuals and families who were seeking a kidney had different reactions such as fear, concern or interest due to financial problem thancadaveric renal transplantation.This kind of reaction was identified by nurses in various meetings and consulting was continued to create acceptance in the family or individual donors and recipients.

"I was under the hemodialysis for years and did not have enough money to buy a kidney.I was opposed to signing up the list of kidney transplant from a cadaver. Then, organ transplant nurse consulted me and convince me that it was better to receive the kidney from a deceased donor than a living donor.I accepted it and received the kidney. "(Patients with transplanted kidney).

**Discussion**

The results of this study showed that the negative attitude of some nurses and physicianshad a negative effect on the family`s decision for kidney donation from deceased ~~donor and brain death.~~ Therefore, nurses were trying to change their attitude and believe to receive a consultation. There is a relationship between nurses and physicians' attitudes toward organ donation with their self-confidence satisfying families (24).Manzari et al found that failing to approve definite brain dead by physicians and nurses, may cause concern, doubt, and lack of trust to team care which was followed by conflict in family`s decision (25).Flodén et al (2011) in their study found that 50 percent of ICU nurses were aware of brain death and were able to give good consultations to their families (26). Therefore, counseling and education are able to change nurses’ attitudes toward organ donation and have a positive impact on the families’ decision for organ donation (24,27).

Another role of nurses was giving consultation to individuals and families with brain-dead patients or those who were in need of kidney transplantation. Most families did not believe in organ donation.The reasons were disfiguring after brain death, the family falls into trouble in the process of organ donation,relative’s pessimism and religious prejudices. These factors lead the needy to buy a kidney from the market.At this time nurses in the role of the consultant were preventing it. Zohoor et al (2003) found that the biggest reasons of dissatisfaction were religious issues, frustrating the family and the possibility of commercial abuse of body organs (28).

Regarding empathy, a number of nurses who had an understanding of the mourning stages, ~~including denial, resistance, bargaining, acceptance, or aggression~~, prepared the individual and family members at the right time to accept the reality. The results of Mills and Koulouglioti(2015) were consistent with our results. They found that preparing families for organ donation requires the nurse‘s support (29). Also, earlier studies showed that giving enough time to the family members to accept the death of their ~~be~~loved ones before the request for organ donation is the most important factor influencing their decision (10, 30).

Manzari et al showed that religious beliefs was an obligation to maintain the sanctity of dead,prohibits the mutilation of dead,the belief to difficulty in the bodily resurrection with organ donation,the belief in the God willing,andtransferring the sins of the donor to the receiver were among most important barriers to organ donation decision (25).

In relation to the nurse`s mediation role, nurses in long-term care of patients had more time to interact with their families.This makes a nurse a bridge to exchange views of the family and physician about kidney donation.On the other hand, in the role of mediator, nurses play a great role in middling the kidney donor and the recipient’s family members.GyllströmKrekula et al study (2015) confirms the results of the recent study.Based on a designed model through the reconciliation of nurses in the intensive care unit, they provide a connecting bridge to organ donation between family members, physicians, and other relevant units (31). In relation to motivating to donate or receive a kidney from a cadaver,nurses provide spiritual, financial and social rewards trying to provide incentives for kidney donation. In order to create spiritual motivation, families with brain-dead patients were invited to meetings of organ donation.Zohoor and Pir (2003) found that nurses and physicians providing motivational factors such as an appreciation of the family members to make organ donation, to show excruciating lives of patients who received transplants and to show the lives of recipients following transplantation, were prepared the ground for organ donation (28).

Studies show that kidney transplantation is expensive and high costs are a major concern for kidney transplant providers (32-33).In the present study along with spiritual and social motivation, sometimes nurses’ support donors and recipients financially.

In the present study culture making and setting up virtual sites in the community were among the nurses’ activities to create motivation for kidney donation which was performed at the community level.Muliira and Muliira (2014) suggested that nurses can invite missionaries and religious clergymen to motivate organ donation decision in individuals and families (34).This was contrary to the results of our study and the participants did not mention it.

One of the themes found in the present study was accepting to receive and donate a kidney from deceased donor and brain dead patients.Also in our study it was determined that the important factor to accept kidney donation by the family members were altruism and a sense of humanity to help others. Roodnat et al (2010) in their study found that an important factor in the acceptance of kidney donation was the sense of humanity among donors and transplant recipients (35). The study of Zohoor et al (2003) showed that one of the main reasons for organ donation was a sense of humanity (28). Also Simpkin et al. (2008) found that;correct understanding of brain death,no request for organ donation at the time of brain death,giving sufficient time for consultation and decision-making to family members,express the request privately and using a consultant nurse as responsible for coordinating to organ donationcould be effective to make the right decision to make organ donation (36).

The general conclusion of this study wasthat the nurses with counseling, empathy, and mediation motivate families with brain dead patients to donate kidneys and also prepare the recipients to receive a transplanted kidney from a cadaver. The results of this study can guide nurses’ interventions in intensive care units and dialysis department to help individuals and families decide to donate or receive a kidney from a deceased donor or the brain dead patient.

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Conflict of interest

The Authors declares that there is no conflict of interest.

Authors’ Contributions

Dr. Jamal SeidiandDr .ShahramBaraz were the main investigator and contributed to development of Study concept and design, Acquisition of data, Analysis and interpretation of data and Drafting of the manuscript.

Salam Vatandostcontributed to development of Study concept, Analysis and interpretation of data and Drafting of the manuscript.

All authors have read and approved the final manuscript.

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