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The Nurse's Role in Decision Making in Kidney Donation and Transplantation: A Qualitative Research

Jamal Seidi¹, Shahram Molavynejad^{2*}

¹Clinical Care Research Center, Kurdistan University of Medical Sciences, Sanandaj, Iran

²Nursing Care Research Center in Chronic Diseases, School of Nursing and Midwifery, Ahvaz Jundishapur University of Medical Sciences, Ahvaz, Iran

ABSTRACT

Background: The decision to donate an organ, particularly kidney, is extremely challenging and influenced by various factors. Nurses can play a major role in decision-making.

Materials and methods: A qualitative design using conventional content analysis approach was used to collect and analyze data. Participants (n=25) were twelve nurse consultants, four physicians, three kidney donors and six family members of patients with brain death were selected using a purposive sample method. A total of 26 semi-structured interviews were conducted. Data were analyzed using MAXQDA 10.

Results: Five main themes emerged from this analysis: Counseling (sub-themes: Individual counseling, family counseling), empathy (mutual understanding, continued support of the individuals and the families), mediation (nurse mediation between families and physician, nurse mediation between donor families and recipients of transplanted kidney families), motivation (spiritual motivation, financial motivation, social motivation) and acceptance of kidney donation (accept to pay a donated kidney, accept to receive a donated kidney).

Conclusion: The study indicated that the care and treatment team could play a significant role in the deceased family's decision and direct their consent to donation. In this regard, family support and communication with them are mandatory when applying for a donation.

Key words: Nurse, Decision-making, Kidney transplantation, Organ donation, Qualitative study

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Corresponding author: Shahram Molavynejad **e-mail** : shahrambaraz@aiums.ac.ir

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INTRODUCTION

End stage renal disease (ESRD) is a chronic and progressive deterioration in renal function when body fails in its ability to maintain metabolic, fluid, and electrolyte balance [1]. One of the curative treatments for patients with advanced kidney failure is kidney transplantation. Kidney transplantation improved quality and quantity of life at a lower cost compared to chronic dialysis [2,3]. Nowadays, the greatest challenge in kidney transplantation is organ shortage; hence, using deceased donor is increasingly encouraged [4-6].

Annually, there are 15,000 accidental brain-dead cases in Iran, of which, less than 10% of the families agree to donate organ, while many people die in need of organ transplant [7]. The organs from these individuals could be used to improve the quality of life, reduce the cost of treatment and care of patients in need of them [8]. 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 [9]. In Iran, for the use of brain death individuals' organs, the will of the deceased person, this can be as donation card, and the family's consent to brain death are needed [7].

Studies have shown that family dissatisfaction is one of the key factors in the kidney donation crisis [10,11]. The organ donation process depends on the families' decision, which is, in turn influenced by several factors [12]. Studies show that family understanding of brain death is not always consistent with legal and medical definitions, and family information is limited in this area [13,14]. It is also argued that families confuse brain death with other brain conditions such as coma and vegetable life [14]. In this regard, the methods by which nurses explain the issue of brain death are one of the most important aspects of nurse communication with family members [15]. Additionally, professional communication and mutual understanding in the treatment team are essential for a successful process and preventing organ loss for transplantation [16]. It has been argued that presence of nurses near the beds of patients can provide many opportunities to influence the ability of the family to adapt to brain death. If nurses can

manage the families of these patients well, they will deal with the death of their patients easier and more effectively, and the probability of their consent to organ donation will increase [17]. Clinical support for brain death donors considerably differs from other patients in critical situations so that requires skilled and experienced caregivers such as physician and nurses who care for professional donors [8]. It is estimated that between 17% to 25% of organ transplants are eliminated due to inappropriate donor management during the critical care period [18]. Furthermore, there is evidence that only knowledge and attitudes about the participation of health providers (including nurses and doctors) do not affect the process of preparing family members for organ donation; however, their experiences may also play an important role and negatively affect the mentioned and reduce the organ donation [19]. Health care providers, including nurses, are more likely to be involved in organ donation in brain death patients. In addition to the importance of caring for brain death patients who are potential donors to maintain organ function, the organ donation process is a complex, vital and sensible process that can only be conducted with high quality nursing care so that is completely based on the final outcome of the organ and tissue transplantation process [20]. Therefore, it is essential to recognize the role of nurses in the organ donation process. Moreover, given the impact of this subject on social-cultural conditions, and given that the best strategy for understanding and explaining social contexts in relation to any social phenomenon is to examine the interactions and experiences of those who experience this phenomenon in their daily lives. Thus, this study aimed to explain the role of nurses in the organ donation process.

METHODS

Objective

This study aimed to explore the nurse's role in decision-making in kidney donation and transplantation.

Research design

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

Participants and setting

The study was conducted during 2015-2016. A purposeful sample of 25 participants (twelve nurse consultants, four physicians, three kidney donors and six family members of patients with brain death) was drawn from Golestan hospital affiliated with Ahvaz Jundishapur University of Medical Sciences and Kosar hospital affiliated with Kurdistan University of Medical Sciences, Iran

Considering the fact that at the transplantation centers of these two universities, there are twelve nurses working as nurse donors, then nurses and doctors from these two universities were selected. To select donor members from a list in the center, sampling was conducted. A targeted method was used to select family members of patients with brain death. Those who were selected as contributors had lived experiences of encountering brain death and organ donation, as well as interacting with the recounting their experiences. They were interviewed after giving informed consent.

Data collection

Semi-structured interviews were held for data collection. This method, compared with the quantitative data collection methods, leads to a more in-depth understanding of the intended phenomenon. Interviews were begun by asking questions such as, 'What is your experience in helping an individual or family for organ donation? Additionally, probing questions such as "Tell me more about this? What does this mean? Please explain more, can you provide us with your experience to understand it better" 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 not addressed during the interview. Data collection was terminated once data saturation was achieved and no new category was extracted from the collected data [21]. Interviews were held individually in an interview room located in hospital. The interview place with the family of brain death patients was determined by their opinion, which was mostly in a private room in the hospital. For some families, they were interviewed at their home. Interviews of physicians and nurses were also conducted in a private room in the hospital. All interviews were recorded through a digital sound recorder and were immediately transcribed verbatim. The length of the interviews ranged from 30 minutes to 90 minutes.

Data analysis

The data collection and data analysis processes were conducted concurrently. To analyze the study data, the Morse and Field's qualitative content analysis approach was employed [22]. MAXQDA 10 was used for content analysis.

Immediately after each interview session, the interview content was transcribed verbatim. Each transcript was read several times in order to immerse in the data and achieve a general feeling about them. Then, the content of each interview was broken to basic meaning units, the irrelevant pieces of data were discarded, and the text was coded line-by-line. 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. It should be noted that translations were in Persian and later translated into English.

Rigor

To ensure credibility of this study, 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 data accuracy, 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 the 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 that participants and observers had access to them. Maximum variation of sampling also confirmed the conformability and credibility of the data.

Table 1: Examples of coding, subthemes and main themes

RESULTS

Five main themes emerged from this analysis: Counseling (sub-themes: Individual counseling, family counseling), empathy (mutual understanding, continued support of the individuals and the families), mediation (nurse mediation between families and physician, nurse mediation between donor families and recipients of transplanted kidney families), motivation (spiritual motivation, financial motivation, social motivation) and acceptance of kidney donation (accept to pay a donated kidney, accept to receive a donated kidney). 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 (Table 1).

	Main themes	Subthemes	Examples of coding emerged by meaning units
The role of the nurse in the individual and family's decision to donate a kidney	Counseling	Individual counseling	As intensive care unit (icu) nurses, we faced many challenges to answer the questions of families about organ donation. Generally, the nurse counselor counseled each of us in-person or on the phone (icu nurse).
		Family counseling	Families of kidney donors faced many ethical challenges. I tried to help them in making decision by putting forward practical solutions through regular follow-up and counseling sessions (nurse consultant).
	Empathy	Mutual understanding	First, i did not agree to donate my brain-dead child's organ. However, after getting plenty of counseling i reached a mutual understanding with nurses and physicians about organ donation (father of a brain-dead child).
		Continued support of the individuals and the families.	I was in contact with families of brain-dead patients and checked their psychological, mental, and spiritual conditions on the phone or in person to support them in making decision about organ donation (a nurse consultant).
	Mediation	Nurse mediation between families and physician	As the mother of a brain-dead child, i wanted to know who the recipient is. Instead, the nurse counselor changed my attitude in several counseling sessions and convinced me to remain anonymous (mother of a donor).
		Nurse mediation between donor families and recipients of transplanted kidney families	The nurse told me that i could save the lives of two patients by donating my brain-dead child's kidneys. It strengthened my faith and i agreed (father of a brain-dead patient).
	Motivation	Spiritual motivation	We cover all medical expenses and even transportation and traveling costs of the donors. It was a kind of financial incentive for them (a nurse counselor).
		Financial motivation	In various educational and counseling sessions with students and public servants in sanandaj, we convinced about 100 people to register in the organ donation association and receive organ donor cards (a nurse counselor).
		Social motivation	As nurse counselors, we knew when the mourning period for the brain-dead patients ended and the families reached the stage of accepting reality and getting ready for organ donation after passing through the denial, resistance, and bargaining stages (a nurse counselor).
	Acceptance	Accept to pay a donated kidney	In counseling sessions, the kidney recipients wanted to clear their conscience by
		Accept to receive a donated kidney	ensuring that nobody was hurt in the process. We convinced them to accept the donation by providing them with clarification (a nurse counselor).

Counselling

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, therefore nurses as the advisor attempted 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, having a negative impact on

family decisions. We had made a number of counseling sessions to change their attitudes" (Nurse Consultant 1).

Another nurse role as a consultant was to provide family counselling at a time when she was not able to make a decision to receive 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 that nurse, who convinced them finally after several counseling sessions; my son's organs including his kidneys are now in other bodies of

people who are in need of it" (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 purchase a 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 individuals and the families. Families of brain-dead patients experienced various reactions ranging from denial, resistance and, ultimately, depression and acceptance of the reality. In fact, some nurses familiar with mourning stages consulted families and 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 accepted that her son was a brain dead. After this stage, we talked to her about organ donation, which was highly 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 created a link with my family" (Mother of a brain dead child).

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. Nurses as a bridge connect different people, physicians, families, kidney donors, and recipients.

"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 an organ donation" (physician 1).

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

Motivation in the individual and family members

This theme was extracted from two categories, motivation for kidney donation and motivation for accepting a donated kidney in spiritual, financial and social dimensions.

"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", (Nurse Consultant 5).

Another role of nurse in creating motivation was to involve families at grassroots organizations.

"In the organ donation unit we prepared a list of candidates for organ donation. In forums, meetings and conferences donors were introduced as heroes" (nurse consultant 4).

Creating financial motivation (a kind of inducement) for kidney donation was another way that the nurses used in some cases. This type of motivation was often used for poor and low-income families.

"Due to financial problems, father of a brain dead patient did not agree to make organ donation. The hospital manger assisted me to pay 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. 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 be accepted.

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

Individuals and families who sought a kidney had different reactions such as fear, concern or interest due to financial problem than cadaveric renal transplantation. Nurses in various meetings identified this kind of reaction and consulting was continued to create acceptance in the family or individual donors and recipients.

DISCUSSION

The results of this study showed that the negative attitude of some nurses and physicians had a negative effect on the family's decision for kidney donation from deceased. Therefore, nurses attempted to change their attitude and maintained to receive consultation. There is a relationship between nurses and physicians' attitudes toward organ donation with their self-confidence satisfying families [23]. Failing to approve definite brain

dead by physicians and nurses, may cause concern, doubt, and lack of trust to team care followed by conflict in family's decision [24]. It also shows that 50% of ICU nurses were aware of brain death and were able to give good consultations to their families [25].

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. It has been suggested that the shock and disbelief experienced by relatives may be minimized if they are aware of the process leading to confirmation of brain death. These factors lead the needy to buy a kidney from the market. At this time nurses in the role of the consultant were prevented it. Zohoor et al. found that the major reasons of dissatisfaction were religious issues, frustrating the family and possibility of commercial abuse of body organs [26].

Regarding empathy, a number of nurses who had an understanding of the mourning stages, prepared the individual and family members at the right time to accept the reality. The results of Mills et al. were consistent with our results. They found that preparing families for organ donation requires the nurse's support [27]. Furthermore, earlier studies showed that giving enough time to the family members to accept the death of their loved ones before the request for organ donation was the most important factor influencing their decision [10,28]. It was show 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, and transferring the sins of the donor to the receiver were among most important barriers to organ donation decision [7].

In relation to the nurse's mediation role, nurses in longterm care of patients had more time to interact with their families, making them as 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 crucial role in middling the kidney donor and the recipient's family members. Gyllstrom et al. study 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 [29]. The more positive the ICU staff members' attitude to organ donation, the greater their efforts to ensure that consent is forthcoming. In order to create spiritual motivation, families with brain-dead patients were invited to meetings of organ donation. Zohoor et al. 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 receiving transplants and the lives of recipients following transplantation, prepared the ground for organ donation [26].

Studies show that kidney transplantation is expensive and high costs are a major concern for kidney transplant providers [30,31]. In the present study along with

spiritual and social motivation, sometimes nurses' support donors and recipients financially.

In the present study, culture building and developing websites in the community were among the nurses' activities to create motivation for kidney donation performed at the community level. In line with the results of the study, it has been reported nurses can invite missionaries and religious clergymen to motivate organ donation decision in individuals and families [32].

One of the themes found in the present study was accepting to receive and donate a kidney from deceased donor and brain dead patients. Furthermore, in our study it was found 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. in their study found that an important factor in accepting kidney donation was the sense of humanity among donors and transplant recipients [33]. The study of Zohoor et al. showed that one of the main reasons for organ donation was a sense of humanity [26]. Moreover, 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, expressing the request privately and using a consultant nurse as responsible for coordinating organ donation could be effective to make the right decision in order to make organ donation [34].

CONCLUSION

The conclusion of this study was that the nurses with counseling, empathy, and mediation motivate families with brain dead patients to donate kidneys and also prepare the recipients in order to receive a transplanted kidney from a cadaver. The results of this study can guide nurses' interventions in intensive care units and dialysis department in helping individuals and families to decide on donating and receiving kidney from a deceased donor or the brain dead patient.

ETHICAL CONSIDERATIONS

This study was approved by the ethics committee of the Ahvaz Jundishapour University of Medical Sciences (ethical code: IR.AJUMS.REC.1395.247), 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. Oral informed consent was obtained from them for recording the interviews and publishing their experiences.

Given that interviews with mournful families could create tension in them, the necessary facilities were provided to all the participants for access to the counselor, which, of course, no case occurred in this regard. Additionally, to encourage nurses and doctors to participate in the study, some gifts were considered that were given at the end of the research. However, families with brain death patients

were interviewed in a completely voluntary manner without any incentive.

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AUTHORS' CONTRIBUTIONS

Dr. Jamal Seidi and Dr. Shahram Molavynejad 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. All authors have read and approved the final manuscript.

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CONFLICT OF INTEREST

The Authors declares that there is no conflict of interest.

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