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Organ donation and gender differences: A qualitative study of female donor experiences

Vaishaly Bharambe[1], Vatsalaswamy Puranam[2], Manvikar Purushottam Rao[3]

Symbiosis Medical College for Women, Symbiosis International (Deemed) University[1]
Dr D Y Patil Medical College, Hospital and Research Centre, Pune, India[2,3]

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ABSTRACT

Living organ donation is an important contributor to the total organ transplant activity carried out in the world. However, there is a clear gender imbalance in the donation activity with more female donors compared to male donors. The present study researched into causes for this phenomenon observed worldover. A total of 26 female donors and their relatives participated in the study wherein interviews were conducted with each to understand the factors that influenced the decision of organ donation. In this qualitaive study it was found that there is a deep influence of the family on the decision to be an organ donor and often such a decision was taken by the family. It is possible that the female donors find it difficult to refute such a group decision. These decisions are also influenced by cultural norms, traditional gender roles of homemaker and bread earner. The decision to donate is also influenced by relation with the recipient and simultaneously with related socio-economic influence. The decision when the donation is within the family, has a positive influence on the mental as well as social status of the female donor and such a benefit could be a factor influencing the decision. The study emphasizes again on the willingness of the female gender to risk life to save or reduce the suffering of a fellow human being. It was observed that while all potential live donors have been apprised of the possible risks of surgery, the data itself is unreliable as there is not much follow up being done of the health status of the donors. This is especially true in India. There is a necessity to keep a regular update on the health status of the live organ donors so that more reliable data in this regard is generated. None of the donors had received any compensation for the organ they had donated but a few expressed that a compensation in the form of regular health checkup after surgery would be welcome.

1. INTRODUCTION

Living organ donation has been an important pillar of organ donation activity. While organ donations after brain death (DBD) or after cardiac death (DCD) have become important as larger sources of organs from a single donor, live organ donation continues to be an important option for obtaining organs for transplant

especially in the underdeveloped countries [1- 3]. Despite more organs being obtained following DBD and DCD, statistics find that live organ donations are increasing. 37.3% of all kidney transplants carried out in 2019 were from live donors [4], [5]. The shortage of organs for transplantation has resulted in a lot of interest in living donor transplantation. Careful donor selection in this case has become a challenge. A four-step evaluation protocol is being used in the careful process of donor selection [6]. Everyday new donor protocols are being introduced to increase the living donor pool. This makes it necessary to research into influencers of decision of living donor decision making [7]. Regarding live organ donors, Dobson observed that women are more often live organ donors than men. He stated that this could be due to their being more vulnerable to subtle pressures [8], [9]. Vieja found that there was a gender imbalance in live organ donors. According to the Annual statement by the Spanish Organization for transplants, at one point 64% of live donors were females and 36% males but 60% of recipients were males and 40% females [10], [11]. Biller-Andorno commented on this state as a medico-ethical problem and stressed on necessity for protection of these vulnerable potential donors and an equitable donor-recipient ratio [12]. Bruneel stressed on necessity for precautions to ensure that the numerous live donors act of their own free will [13]. Sahay stated that in India too, majority of living donations are from female donors and majority of the recipients were males [14].

The present research explores this gender difference through discussion with female organ donors and her relatives (if any) and attempts to understand their perspective about the reasons for her becoming a live organ donor.

1.1 Research question

What is the reason behind more number of female live organ donors?

1.2 Methodology for conducting the research

The study was undertaken in Pune District of Maharashtra which is a large state in India. At the time of commencement of the study, the region had about 18 Hospitals, in 5 cities of the district, which were sanctioned to carry out transplant surgeries.

Independent ethics committee clearance was obtained to conduct the study.

Study design: Qualitative, through in-depth interviews.

All Female donors and their relatives were approached through the Hospitals and requested to participate in the study. They were assured of complete confidentiality of identity. Inclusion criterion for participating in the study was that the participant must be an adult, over 18 years of age, a female live organ donor or her relative and willing to give consent to participate in the study. All live organ donors or her relatives who were not meeting above criterion were excluded from the study. A list of questions was created. This was used as a guideline while conducting the semi-structured interviews both for the female live organ donor as well as for the relatives consenting to participate in the study. In depth interviews were conducted with all the participants individually. The discussions were conducted in places where the participants could be comfortable with no chance of being overheard by anyone. They were conducted in languages in which the participants were proficient. They were conducted in English, Hindi (the National Language of India) as well as Marathi (the local language used in the State of Maharashtra).

Written consent was obtained from the participants before commencement of the discussion.

First the participant was provided with an overview of the questions. During each interview, the participants were allowed to set the pace of the discussion while sharing their experiences before, during and after live

organ donation. The donor participants were gently probed to get the details of their perspective about why they had become live organ donors and other aspects of the live organ donation. All participants were encouraged to share any advice or suggestions in relation to organ donation. The interviews were noted during discussion.

Transcripts of the interviews were created. They were analyzed following the grounded theory for analysis of Qualitative data. The emerging themes were used to get insight into the experiences leading to a live organ donation by a female donor. This qualitative research was carried out to point of saturation.

2. FINDINGS AND DISCUSSION

Out of the 45 female live organ donors approached to participate in the study, 8 female donors and 18 relatives consented to participate in the study. The details are depicted in Table 1.

Table 1: The details of participants and their relations to each other and the recipient

S. No	Donor (Age)	Marital status	Donor's relation with the recipient	Relative of the Donor participating in the study	Type of organ donated
1	Female (23 yrs)	Unmarried	Uncle (Mother's Brother)	Mother	Kidney
2	Female (21yrs)	Unmarried	Sister	Mother, Father, Elder and Younger Brothers,	Kidney
3	Female (37 yrs)	Married	Husband	Husband, Mother-in-law, Brother-in-law	Liver
4	Female (31yrs)	Married	Husband	Mother, Brother	Kidney
5	Female (42 yrs)	Married	Husband	Father	Kidney
6	Female (43yrs)	Married	Brother	Husband, Brother, Sister-in-law	Kidney
7	Female (20 yrs)	Married	Brother in law	Husband	Kidney
8	Female (51yrs)	Married	Son	Husband, Son, daughter-in-law	Kidney
Total	8			18	

Each of the female donors as well as their relatives was interviewed separately. The interviews of female donors were time consuming and many of the donors got very emotional during the discussions. Many of the relatives, in a few cases themselves being the recipients also found themselves emotionally drained at the end of the discussion. It was noted that each participant in the present study had come to willingly share their experiences which they believed were unique and needed to be shared with the world.

The information revealed by the female live organs donors is outlined in Table 2.

Table 2: History of 8 Female live organ donors in relation to the organ donation

Case 1	The donor and her widowed Mother had been staying with her Uncle (Mother's Brother) for a long time and were dependent on him for support. He had been suffering from Kidney failure for almost 2 years and was undergoing twice weekly dialysis. While he was married and had 2 adult sons, it was expected that a member of the dependent family would become the donor. The female donor's Mother had been ailing and hence she consented to be a donor of a kidney.

Case 2	This was a family of 6 people, consisting of parents, 2 daughters and 2 sons out of which one of the daughters was in kidney failure. In this case the 3 males of the family were not considered for organ donation as they were working hard to provide for the home. Hence the Sister of the patient volunteered to be the organ donor to save the life of the sibling. The donor also reported that her marriage prospects were now very reduced as other families do not want a daughter-in-law with only one kidney
Case 3	The female donor reported that in this family of 5, made of 2 parents, a Son, Daughter-in-law (herself) and one child, the family just assumed that she would be the donor as it was her husband who was in liver failure.
Case 4	The female donor reported that the family just assumed that she would be the donor as it was her husband who was in kidney failure.
Case 5	The female donor clearly stated that she refused all offers from family members of willingness to be donor for her husband from the family as she wanted to be the organ donor for her husband
Case 6	The donor donated her kidney willingly to her brother. She was very worried about her brother whom she did not want to lose.
Case 7	The donor had been married for over one year when her younger Brother-in-went into kidney failure. She was advised by all the family members to agree to live organ donation. No option to refuse was offered.
Case 8	The donor donated an organ to her son, as other members of the family were male and had to work hard to earn a living to support the family. This family consisted of elderly father-in-law, mother-in-law, parents and 3 sons.

Themes:

Irving et al have reported a number of factors influencing the decision to be an organ donor. These include relations within family, culture, religion, effect of previous encounters with health care system among others [15].

In the present study a thematic analysis was carried out and a number of themes emerged during the discussions. The discussion is now presented under these themes.

2.1 Influence of Family structure

Ya-Ping Lin stated that family structure and relationship between donor-recipient-caregiver shape the decision making process in live organ donation [16]. Becoming a live organ donor is not an individual decision of either the donor or the recipient but a combined decision by the family influenced heavily by the socio-economic conditions, cultural norms, socially influenced gender roles and division of labor within the family. Kotler-Klein stated that there is a lack of knowledge and understanding about the family process happening in living donation, its consequences and rewards and influence on the family dynamics [17]. As per the THOA Act 1994, the decision of Organ donation from a brain dead donor needs consent of near relatives of the donor [18]. However for live organ donation while consent of near family members is required, the decision to donate an organ while being alive is primarily that of the donor. In the present study, in all cases but one, the donor and recipient belonged within the same family. In six of the cases the decision to donate an organ to a family member was taken as a family decision. While not openly admitting to coercion, many of the female donors admitted to pressure from the family. Stressed upon the intertwining of socio-cultural and biological issues as pivotal points affecting organ donation [19]. Risks of the surgery, as well as dependencies within the family structure, generate pressure on the potential donor [20]. Jacobs studied the effect of live organ donation on the family of the live donor and found that, the donors have increased self worth and a positive self esteem but also reported that the organ donation was felt as very stressful when the donors were females [21].

In the present study in case 5, the female donor and the relatives reported feeling of satisfaction and increased position within the family after becoming the organ donor for her husband. In a study related to living kidney donor decision making and outcomes, it was found that the satisfaction with donation could be related to biological or emotional relationship with the recipient [22].

2.2 Relation with the recipient

Married donors were more likely to include family members in their decision to be live organ donors. But here when the family includes the recipient, then the transplant professionals must be vigilant against coercion of the donor by the recipient [22]. In the present study, six of the participant donors were married. While 5 of them donated organs to their spouses or to family members within their spousal family, one donated an organ to her own brother. This case needed support and consent of her spouse who was extremely supportive of the decision. The donor did not face any problem at her marital home regarding her decision of donating a kidney to her brother. Her husband when interviewed stated that he felt immense respect for his spouse for the decision she had taken and that it was important to support the donor. Rota-Musoll observed that women who have a biological kinship with the recipient felt it natural to offer to donate their organs. In contrast the authors noted that when the recipient was a spouse, the female donor donated by their gender conditioning and to avoid taking on the carer role for the ailing spouse. They also did this to protect their children and as a form of empowerment [23]. In the present study in case 3 where the donor had a young child, she stated that she did not resist being expected to be the donor as the survival of her spouse was important for her and child's future.

2.3 Reason for taking decision of becoming a donor

In each case the recipient had been ill for a long time and was suffering with organ failure and this had been observed by the donors. All the female live organ donors stated that illness of the family member or loved one was the important reason for their decision to donate the organ. In a similar study of perspective of organ donors, the most common reason given by the donors for donating an organ was reported to be "because recipient is family" [24]. In a study by McGrath, the authors reported that the donor's primary reason for becoming an organ donor was to relieve the patient of their suffering [25]. Observed that women seem to have more sense of responsibility and will to sacrifice than men [26].

2.4 Feeling informed about risks of becoming a live donor

Many of the donors in the present study had consulted the doctor in charge of the case for advice regarding the risks and possible complications of surgery and after donation of a complete organ such as kidney or part of an organ such as liver. Some were separately counseled regarding risks to their health. However the educated donors read up and empowered themselves on the precautions to be taken to maintain the leftover kidney or liver in good health. Most of the donors and relatives stated that they took a few days after these discussions to come to their decision. Donor assessment must be very stringent in the view of adverse psychosocial outcomes and also occasional donor death [27]. In many countries in Europe and in the USA there is a 'donor advocate' who is completely dedicated to the mental health of the donor. He / she is the person who discusses the pros and cons of surgery, the post operative complications, the family equations, any pressure being applied on the donor etc [28]. Donors should undergo a psychological assessment to analyze their reason for agreeing to be a donor, their psychological health, donor –recipient relationship etc [29]. One donor stated that she was asked by the consulting Doctor if she was being coerced into donating her organ but she was unsure how to answer such a question and had preferred to keep quiet. She stated that she had thought that if her own family had not given her an option, why would the Doctors do so? She went on to state that such a question was again asked by the sanction committee but she had said "no" when addressed individually in front of the rest of the family. The issue of pressure exists especially when the

person is a spouse or any near relation of the recipient. Hence the risk-benefit ratio must be adequately explained [30]. Here the risk to the donor is balanced against the benefit to the recipient and also to the donor. The ratio has to be explained and understood in terms of probability and magnitude of the harm. Before a potential donor takes the decision to be the donor, he or she must have an accurate understanding of the risks and potential benefits associated with the donation [30].

2.5 Health status of live organ donor today and related follow up

All the participant donors were feeling fine and were taking better care of their health knowing that they had only 1 kidney now. However none have undergone any health related physical or mental check up or follow up after becoming an organ donor. Live organ donation developed on ad hoc basis at various transplant centers in India. It has never had a central supervision that has been a part of deceased organ donation activity [31]. Living donors continue to be responsible for optimum outcome for kidney transplant recipients, but there is no study that reflects the effect of the same on the living donor and his or her family [21]. Thus there is a lack of information as is seen in deceased donor programs. It is important to register each living organ donor, to specify the parameters to be followed up over the years. Some of the data to be collected includes physical and mental health of the donor, financial resources, insurance status and experience etc [31]. Usually the information to the potential donor is inevitably inadequate as often the long term health outcome of the particular type of live organ donation is only beginning to be explored. This is especially true in case of non renal live organ donations. Another reason for inadequate information being provided to the potential donor is that the data for such situations has not been collected and analyzed rigorously. There is little long term follow up of donors to study physical and psychosocial effects of living organ donation [31]. For those who have donated liver or lung there is hardly any data available as only recent and short- term studies are available and very little is known about the long term effects of these organ donations.

2.6 Effect of the organ donation on family dynamics

Studies have reported the live donors have a high quality of life and increased feeling of self-worth and self-esteem. There are also reports of changes in family dynamics based on related support, financial impact and changed relationships [21]. Some studies report a notion of reciprocity and indebtedness among family members in relation to organ donation, which also influences the process of decision making [16]. In the present study none of the participants reported any change in family dynamics except the Sister who had donated to her brother. She reported the organ donation brought the two siblings even closer.

2.7 Comments on compensation of live donor

None of the donors interviewed spoke of any monetary compensation having been given. One donor said that they wouldn‘t mind a compensation of some sort or a medical insurance cover in case they have a serious illness due to having only one kidney. However one donor said that there is regular check up of the recipient but no checkup of the live donor who is sort of sidelined after the surgery. The donors did not mention any separate expenses that they were forced to incur as a donor. Iran is a country which has legalized the payment to their kidney donors and this payment is done directly by the Government of Iran. Today it is one of the countries with very few people on transplant waiting list [32]. Under the Transplant of Human organs and tissues act of India, near relatives can donate to an ailing family member in case there is a need [18]. Dar states that it is believed that no financial transactions are taking place at such times and this donation is done out of love and affection for the recipient [33].

2.8 Advice or suggestion

Most were happy with the way things were handled. Especially one of the donors who had a very

interactive nephrologist, were completely satisfied with the patient care they experienced. However one family felt that there is a need to streamline the paper verification atthe government level. Also with the patient being so ill, the staff at the government office related to transplants must be very helpful and efficient. The patients are in critical health status and at such times the donor and family members of the recipient find it very challenging to run from pillar to post to get papers and documents to move. A legal cell which only does document verification using all modern falsification detecting software can be created to conduct the verification.

2.9 Constraint

Most of the female donors approached were uneducated and were scared of interacting with the research team and refused to participate in the study.

3. Conclusion

Living organ donation is an important contributor to the total organ transplant carried out in the world. However, there is a clear gender imbalance in the donation activity with more female donors compared to male donors. The present study researched into causes for this phenomenon observed worldover. It was found that there is a deep influence of the family on the decision to be an organ donor and often such a decision was taken by the family. It is possible that the female donors find it difficult to refute such a group decision. These decisions are also influenced by cultural norms, traditional gender roles of homemaker and bread earner. The decision to donate is also influenced by relation with the recipient and simultaneously with related socio-economic influence. The decision when the donation is within the family, has a positive influence on the mental as well as social status of the female donor and such a benefit could be a factor influencing the decision. The study emphasizes again on the willingness of the female gender to risk life to save or reduce the suffering of a fellow human being. It was observed that while all potential live donors have been apprised of the possible risks of surgery, the data itself is unreliable as there is not much follow up being done of the health status of the donors. This is especially true in India. There is a necessity to keep a regular update on the health status of the live organ donors so that more reliable data in this regard is generated. None of the donors had received any compensation for the organ they had donated but a few expressed that a compensation in the form of regular health check up after surgery would be welcome.

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