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## Survey a Knowledge and Consciousness of the Potential Donor Family

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### Abstract

**Introduction:** Study about the knowledge and consciousness of organ donation of the potential donor families to make increasing the consensus of organ donation that is a pressing requirement.

**Methods:** Qualitative research, using a set of 10 questions to assess the consciousness and knowledge of organ donation of the potential donor families to save the patient at Cho Ray Hospital from 1/5/2015 to 30/9/2016.

**Results:** 55 relatives of 54 potential donors included 41/54 (75.93%) male, 13/54 (24.07%) female. The average age is  $38.15 \pm 14.21$  years (youngest 17, oldest 72). 20% have not known yet the information about organ donation and transplantation, > 50% do not agree to donate, 21.82% want to keep their body intact, 49.1% agreed to donate, 56.4% agree to donate if they receive the support from the Government (<20% do not accept it).

**Conclusion:** Understanding the factors have prevented the organ donation decision of the potential donor family, and have the remedy plan for these mistakes. It will make increasing the proportion of organ donation from the community.

**Keywords:** Organ donation rates in a neurosurgical intensive care unit, End-of-Life Conversations with families of potential donors

**Introduction:** The first Vietnam's kidney transplantation was performing 27 years ago. Until 2020, there are 25 transplant centers across the country with more than 3,000 kidney transplantation cases, but mostly from living donors, only have over 200 organ donation from brain dead donors. This is only a very small number on over 10,000 patients on the waiting list and we have not counted the number of patient who died while waiting to receive organs. Survey a knowledge and consciousness of the potential donor family to know the refusal reasons to donate in community. It is an urgency requirement to research, because it can make increasing the rate of organ donation.

**Methods:** Qualitative research, using a set of 10 questions to assess the consciousness and knowledge of organ donation of the potential donor families to save the patient at Cho Ray Hospital from 1/5/2015 to 30/9/2016. Content of 10 questions are included:

- 6 questions about knowledge of organ donation (question number 1, 2, 3, 4, 6, and 7)
- 4 questions about consciousness of organ donation (question number 5, 8, 9, and 10)

Summarizing these results, recognizing the refusal reasons of organ donation, to get learning

and make a plan to be able to increasing the number of organ donate.

**Results:** 55 family's members of 54 potential donors, including 41/54 (75.93%) male and 13/54 (24.07%) female potential donors. The average age of patients were  $38.15 \pm 14.21$  years old (the largest is 72 years; the youngest is 17 years) (table 1).

Table 1: Illustrate the family's members can access

Family's members	Parent	Sibling	Spouse	Children	Relationship	Family	Total
Case	13	12	5	4	7	14	55
Rate (n=55)	% 23.64	21.8	9.09	7.27	12.73	25.45	100.0

Table 2 is illustration the results of interview, according to the question set. These are encoded to 1, 2, 3... that are questions 1, 2, 3...; a, b, c are answers.

Table 2: illustrate the interview results of consciousness of the potential donor families.

N <sup>o</sup> Question	Rate (n=55)
1. In the worst case of the patient, when the doctor tell you that the disease is unable to do anything more, the coma will not recover, (which mean brain death). Have you ever hearing about this issue or not?	
a. Yes, I have it.	78.2%
b. No, I've never hearing that, but I understand it.	18.2%
c. No, I haven't understanding it.	3.6%
2. Have you ever hearing about organ donation after death (Ex: heart, lung, liver, kidney, cornea ...) to save of patients on the waiting list by newspapers, television or not?	
a. Yes, I have it.	81.8%
b. No, I've never hearing that, but I understand it	12.7%
c. No, I've never hearing that, but I don't want to discuss about it.	5.5%
3. Unfortunately, one person died, if he was buried, he would return to dust, but if he would like to become donor. He could save from 5 to 7 patients. What do you think about it?	
a. Can accept it	61.8%
b. Cannot accept it	30.9%
c. Not answer	7.3%
4. In the case of kidney and other organs (heart, lung, liver, cornea ...) donate to transplant, the body will be deficient some parts, what do you think about it?	

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| a. Can accept it   | 56.4% |
| b. Cannot accept it  | 34.5% |
| c. Not answer  | 9.1%  |
| 5. If you are received a question to donate kidneys or other organs for any patient, whom are hospitalized. Can you agree?   |       |
| a. Agree   | 49.1% |
| b. Cannot agree  | 36.4% |
| c. Not answer  | 14.5% |
| 6. Unfortunately for one's from morbidity or accident, which physician cannot be saved them, because of irreversible cerebrum damage. But their organs function are still good, Doctor can use to save patients. Do you and your family agree to organ donate in this situation? |       |
| a. Agree   | 45.5% |
| b. Cannot agree  | 43.6% |
| c. Not answer  | 10.9% |
| 7. According to the principles of organ donation, that donors and recipients should not meet or contact together to prevent the negative manifestations. Do you agree to donate or not?  |       |
| a. Agree   | 67.3% |
| b. Cannot agree  | 9.1%  |
| c. Not answer  | 23.6% |
| 8. Kidney or organ donation to transplant is a deep in the human heart act. It is a noble, invaluable act; so we cannot use anything to exchange. Do you agree to organ donate?  |       |
| a. Agree   | 67.3% |
| b. Cannot agree  | 9.1%  |
| c. Not answer  | 23.6% |
| 9. Following the same noble principle, no money or anything from recipient will be accepted. But if there is a Charity or Government budget to support this issue. Can you accept it?  |       |
| a. Accept it   | 56.4% |
| b. Cannot accept it  | 18.2% |
| c. Not answer  | 25.5% |
| 10. In addition to kidney donation, you can also donate other organs: liver, lungs, heart, pancreas... to save of live for more patients. Which solution do you choose?  |       |
| a. Multi-organ donation  | 49.1% |
| b. Kidney donation only  | 1.8%  |
| c. Do not agree to donate  | 49.1% |

While interviewing 55 relatives of 54 potential donors, one of all asked the coordinator, that is "I know organ donation is a humanitarian action, but what can be sure that the doctor doesn't bring my father's organs to sell?" The coordinator has explained their process to donor's son. After that, they agreed to donate. In this case, we received 1 liver, 2 kidneys and 2 corneas.

In addition to this case, Cho Ray Hospital also received the organ donation from other 9 families, but had to reject 5 cases, because the donor had contraindications to organ donate for transplantation (table 4).

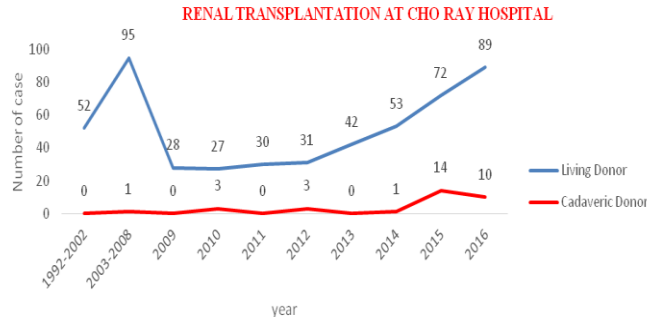
**Table 3:** Illustrate the refusal reasons of the potential donor families.

The refusal reasons of the potential donor families	Case	Rate % (n=55)
To want the body donor's integrity	12	21.82
To want the donor's heart still beat when he come back	1	1.82
Do not want to bring more painful to donor	3	5.45
To advise donor family against to donate from the other one	3	5.45
Not decided yet	2	3.64
Lack of information	1	1.82
Depends on the decisions of the other one	9	16.36
Do not want to deal with organ donation	3	5.45
The potential donor hasn't any comment about that before	2	3.64
The sadness of the family	2	3.64
Understanding, but refusing	3	5.45
Local culture	1	1.82
Do not want to get a bad name as an organ trafficking	2	3.64
To meet the recipient	1	1.82
<b>Total</b>	<b>45</b>	<b>81.82</b>

**Table 4:** Illustrate the reason didn't receive the organ donation with their families

Reason refuse	Case	Rate % (n=55)
Vegetative status	1	1.82
Pneumonia	1	1.82
HIV	1	1.82
Syphilis	1	1.82
Activation of Hepatitis B	1	1.82
<b>Total</b>	<b>5</b>	<b>9.09</b>

**Discussion:** The kidney transplantation from brain-dead donors (DBD) was performing in the world 46 years ago (1962-2008). The first case of DBD performed on 23th April 2008 in Vietnam after the "Law on donation, removal and transplantation of human tissues and organs and donation and recovery of cadavers"<sup>[0]</sup>. But since that time, the number of organ donation from DBD has still not increasing in Vietnam. According to the report of Cho Ray Hospital (2016)<sup>[0]</sup>, the number of organ donations from living donors and DBD has been increasing, but it is fluctuation (graph).



**Graph:** The number of donors at Cho Ray Hospital, (Data source from Du Thi Ngoc Thu et al., (2016), “Organ donation and transplantation at Cho Ray hospital: Present and future”, HCMC Medical J., vol.4, supp. 20, pp.18-25. ISSN 1859-1779.<sup>[0]</sup>)

According to the chart, during the first 15 years (1992-2007) of the organ transplant program, only 147 cases were donated from living related donor, there were no cases of brain dead donors. When the law on organ donation was introduced (2008), one organ was received from brain-dead donors. It was not until 2 years later (2010) that another 3 cases were kidney donation, and another 2 years later, there were 3 more cases of organ donation ... during this period, It is fortunate to get donation consensus of the potential donor families, because of donors were whom always working anything by heart themselves in the past. After more than 5 years of communication, Cho Ray Hospital has received some positive results so far: 13 cases of cardiac death donors, and 21 cases of brain death donors, and received over 13,700 letters of tissue-organ donation register from the communities (Oct. 2014 to Feb. 2020).

The number of Vietnamese is over 90 million people, but currently there are only over 30,000 letters of tissue-organ donation register from the communities, accounting for 1 in 3,000 people. Therefore we need a plan to increase the organ donate as same as the body donate program for medical students to research (currently over 30,000 people have registered to donate their bodies). Organ donation is completely different from donation of the body, requiring the consent of the family in the most distressing moment, so it needs the waiting time for family to make decision. It were the most important things of organ donation process. Therefore, the first step of plan are understanding of reasons which are hindered the family's decision at the last moment and to have a plan to overcome it. The tables 2 and 3 noticed:

- Questions 1 and 2: Appropriate 20% the potential donor families didn't understand the information of organ donation after death.

- Questions 3, 4, 5, 6, 10: The ratio of consent to organ donation varies in a descending direction until the decision to donate in question 10 is 49.1%. However, this is only theory; because after completing the questionnaire, the family signed an application for discharge. This shows that from the hypothesis to practice, there are huge distances and there are many causes of hindrance.
- Question 4: Appropriate 40% the rate of families want the body donor's integrity. These are the organ donation refutation highest ratio in this study (21.82%, table 4). The Shinto religion is the only exception, which saying that it is a serious in to violate the bodies<sup>[0]</sup>.
- Question 5: Over 50% the potential donor families were disagreed with organ donation or do not answer. If the patient hadn't registered previously by himself, then the refutation would be their family's natural response.
- Question 8: Organ donation agreement with exchange something between is a big problem in Vietnam now. In theory, the donation doesn't require any exchange in it. So, How to pay hospital fee for donor hospital? This is a problem that needs to be save.
- Question 9: 56.4% of families were agreed to accept organ donation if there are funding from the Government or Charities. <20% don't want to receive any funding, the rest of them do not respond.
- Question 10: 49.1% disagree organ donation. This proves that in the embarrassment situation of their family, if there hasn't the donor previous wish, the family refusal rate will be very high.

Hoang Thi Diem Thuy et al. (2016)<sup>[0]</sup>, The 3 beneficiaries, who are: students, Christians, and Buddhists (not in the public health), the rate of agreeing to donate kidneys of their relatives is 63.8%, of their self is 77.0%. There is a difference in the object of this study that the participators whom haven't to confront the risk of lose a relative.

In this study, the rate of multi-organ donation was 49.1%, only 1.8% kidney donation. But in practice, the rate of organ donation was only 3/55 (5.45%). It shows that there are many difficulties and concerns from the thinking to action, especially when we decide on behalf of others.

### **Learn about the factors that hinder the potential donor family's decision to organ donate.**

When someone's dies, its cells can live for only a short time. The organ that can be removed from the body and must be transplanted immediately, otherwise it will die because it is not provided with the substances necessary to maintain the living activities of the cell. Human death can be defined by three different fields: Medicine, Religion and Law. The Vietnamese traditional morality concept is meaning, that "the death means the end", all of resentment is removed when he died. Another humanistarian concept is "life stays on, death is returnee", the life means as a temporization, death is not the end. According to Hoang Thi Diem Thuy et al (2016)<sup>[0]</sup>, the reason refused to kidney donation is anxious about their family disagreeing (44.8%), feeling of fear (27.8%), 19, 6% are other reasons, including the desire to want the body donor's integrity (45/70, 64.28%). According to this study, 45/55 families refused to donate their relatives' organs for various reasons (table 4), but of which the percentage of the body donor's integrity is 21.82%.

The dependent on the others decisions is the second obstacle of this group (16.36%), this obstacle is encountered in the case of:

- The great family, depending on the opinion of grandparents, parents, sibling, spouse, aunts, uncles, etc., these are the practical constraints of Vietnamese customs and practices. But in case the person whom the right to decide doesn't have enough skill, doesn't have enough reason to convince a large group, the asking for organ donation would be considered a failure.

- If the potential donor family depends economically on someone, the organ donation convincingness with family will be fail if they refused.

- Who doesn't have a firm standpoint, he will be moved by the opposite advice of organ donation around him.

- Trust is also one of the factors that hinders a family's decision. Without a protocol to act, and it demonstrated all of activities, that is voluntary, it will be difficult to successfully.

- 2/55 TH (3.64%) been anxious that they will become the trader. These cases are often seen in low-income families. This is also a problem that we are facing everyday in practice. Therefore, the communication, education and positive information are needed for officials and employees in thought of country not only for the community. We must have empathy with them.

In addition, Dong Van He et al (2015)<sup>[0]</sup> they had the survey on knowledge of brain death for who are students in Hanoi Medical University, they concluded that only 16.3 % understand correctly about brain death; 83.7% did not understand correctly it. Medical students are the members of society whom can have to access the medical advances most easily but they have not yet correctly identified of brain death. So the community lack of information is certainly, and this is one of the factors that hinder the decision to organ donation. In fact, 10/55 (18.18%) families interviewed they agreed to donate, because of whom were understanding the meaning of organ donation. Unfortunately, we only received donation of 5 cases (table 4). Besides, the team encountered other factors that were the concepts of customs and feelings for relatives such as: 1.82% would like his heart to beat while going home, 5.45% do not want to bring more painful to donor, 1.82% due to local culture. In addition, the rest are related to information, communication and other issues in society such as: 14.54% undecided, do not want to mention, lack of information, 9.09% knowledge, but refused and because relatives had no previous comments, 1.82% asked to see the recipient. Shemie Sam D., et al (2017)<sup>[0]</sup>, reported of the meeting results with 44 members who are leaders of professional organizations of intensive care, organ donation, social worker, legal, sectarian, ethical, health care management, donor family, local representatives and international experts. With the goal of increasing the consensus of organ donation and the faith of the potential donor family at the intensive care units. The conclusion of experts gave 12 important recommendations and practical guidelines on: the effect of conversations with potential donor families, access to the families on donation, communication on death. or prognosis of a serious illness, information provided to the family, perceptions of the family, legal status, family support, skills and specific characteristics needed for access, and the relationship between the donor hospital and coordination center. The number of organ donation from cadaveric donor increasing will evaluate the successful result of program.

**Conclusion:** To have understanding of the factors that prevent the organ donation decision of potential donor families, that enhances the provision of more positive information, the results of patients after organ transplantation, and transparency protocol, non-profit working for the community, the professional training and education programs for medical officers, students... This will be increase the donation consensus rate of the potential donor families 5-10 times higher than as much as the coordinator convincings do.

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