



# Factors Influencing Families' Decision-Making for Organ Donation in Hunan Province, China

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## ABSTRACT

**Background.** In 2010, the Chinese government started a pilot project of donation after Chinese citizens' death. Seeking the consent of the families of potential donors is an important task in the organ donation process.

**Objective.** We aimed to explore the factors that influence the families' decision-making for organ donation.

**Methods.** We performed a content analysis of 30 semistructured in-depth interviews with immediate family members who made the decision for an organ donation. The interviewees were asked questions such as how the decision to donate was made, what factors influenced the decision, and whether the decision was rejected by relatives and friends.

**Results.** The interviewees were the donors' parent (15; 50%), spouse (9; 30%), brother (3; 10%) or son (3; 10%), including 18 men and 12 women, with a mean age of 41.6 (standard deviation, 10.7) years; rural households accounted for 83.3%. Through analyzing the interview notes, 17 factors were mentioned by interviewees, and 3 types of decision-making in organ donors' families were obtained. Then, the factors affecting the decisions of the donor families were classified into 3 categories and 11 subcategories.

**Conclusions.** Factors influencing the families' decision-making for organ donation were analyzed preliminarily in this study.

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**W**ITH the increasing demand for organ transplant in patients with organ failure, the contradiction between the supply and demand of organs is also worsening. To alleviate this contradiction and to promote the healthy development of organ transplantation, in 2010, the Chinese government started a pilot project of donation after Chinese citizens' death. Seeking the consent of the families of potential donors is an important task in the organ donation process. Jiefu Huang, the Former Deputy Minister of the Ministry of Health, has said that currently, China has no provision of presumed consent; the opinions of immediate family members must be given full consideration in the donation process; the consent of immediate family members should be considered the key factor in formulating the decision of organ donation [1]. Relevant studies have shown that disagreement among family members and their refusal to donate are important causes of the low organ donation

rate [2,3]. This study interviews the immediate family members and conducts a preliminary analysis of the factors that influence the decision-making of the donors' families.

## MATERIALS AND METHODS

### Interviewees

For this study, we contacted 30 family members of organ donors from June 2010 to October 2013 in Hunan Province who were the

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spouses, parents, brothers, and adult children of the donors and agreed to be interviewed.

### Methods and Procedure

First, an interview outline was prepared, and 3 organ donation coordinators with excellent communication skills and a strong sense of empathy were selected as the interviewers. Because the organ donation coordinators have had some interaction with the families in the process of organ donation and were trusted by them, the communication to obtain real and detailed information was relatively easy. The interview time was controlled and was from 45 minutes to 1 hour. A semistructured interview was used. The interviewer guided each interviewee in describing the decision-making process of organ donation in a manner as detailed as possible. For example, the interviewer asked questions such as how the decision to donate was made, what factors influenced the decision, and whether the decision was rejected by relatives and friends. The outline of the interview was designed to be very broad to encourage the interviewee to freely express his or her opinions. During the interview, the interviewer listened carefully to the interviewee's description. According to the interaction with the interviewee, the order of the interview items was flexibly adjusted, and the specific questions of the interviews varied according to the actual development of the interview process.

Notes on the interview were taken as soon as possible after the interview. The interview notes promptly record the scene, the typical performance of the interviewee, and the experience of and inspiration in the interview process to provide a reference for the analysis of the interview data. The interview data were denoted and encoded for statistical analysis to determine the factors that influence the family decision of organ donation.

### Quality Control

The 3 interviewers were intensively trained prior to the interviews so that they fully understood the content and meaning of the interview items, ensuring that the interviews were objective and accurate. During the interview process, the interviewer did not comment on the content of the conversation, and he or she encouraged the interviewees to fully express their opinions, feelings, and experiences, thus obtaining more information. Interview notes were recorded in a timely manner after finishing the interviews. Each document was reviewed twice with repeated adjustment and confirmation to ensure that the interview data were complete and accurate.

The interview notes were jointly encoded by the investigator and another researcher. First, 2 researchers independently encoded the interview data and then repeatedly reviewed these interview data together, discussed the coding until they reached a consensus, and ultimately completed the coding and extracted the concepts for the generic analysis.

**Table 1. Demographic Data of the 30 Interviewees**

Relationship	Age of Interviewee, y	Household of Interviewee	Education Level of Interviewee	Age of Donor, y	Sex of Donor	Cause of Death
Father	48	Rural area	Elementary school	22	Male	Motor vehicle crash
Mother	63	Rural area	Elementary school	30	Male	Motor vehicle crash
Father	48	Urban area	College	15	Female	Glycogen storage syndromes
Father	47	Rural area	High school	17	Female	Brain tumor
Father	44	Rural area	Junior high school	17	Female	Brain tumor
Mother	44	Urban area	Junior high school	14	Male	Motor vehicle crash
Mother	43	Rural area	Junior high school	15	Female	Motor vehicle crash
Father	49	Urban area	High school	20	Male	Motor vehicle crash
Father	37	Rural area	High school	14	Female	Brain tumor
Father	48	Rural area	Junior high school	16	Female	Cerebral hemorrhage
Mother	42	Rural area	Illiteracy	20	Male	Motor vehicle crash
Father	45	Urban area	College	21	Male	Brain tumor
Father	45	Rural area	Elementary school	20	Male	Motor vehicle crash
Father	41	Rural area	Junior high school	15	Male	Poisoning
Father	44	Rural area	Junior high school	9	Male	Motor vehicle crash
Brother	40	Rural area	Junior high school	38	Male	Motor vehicle crash
Wife	44	Rural area	Elementary school	46	Male	Motor vehicle crash
Wife	49	Urban area	Junior high school	50	Male	Motor vehicle crash
Wife	32	Rural area	Junior high school	35	Male	Motor vehicle crash
Wife	23	Rural area	Junior high school	24	Male	Motor vehicle crash
Wife	36	Rural area	Junior high school	39	Male	Brain tumor
Son	23	Rural area	Elementary school	47	Male	Cerebral hemorrhage
Son	26	Rural area	Elementary school	50	Male	Cerebral hemorrhage
Brother	35	Rural area	College	38	Male	Motor vehicle crash
Wife	37	Rural area	Junior high school	39	Male	Brain tumor
Wife	32	Rural area	Junior high school	32	Male	Motor vehicle crash
Brother	43	Rural area	Elementary school	46	Male	Cerebral hemorrhage
Son	19	Rural area	Elementary school	42	Male	Motor vehicle crash
Husband	71	Rural area	Junior high school	68	Female	Cerebral hemorrhage
Wife	50	Rural area	High school	52	Male	Motor vehicle crash

**Table 2. Statistics of the Coding Frequency in the Interviews With the Families of Organ Donors**

Influencing Factor	No. of Organ Donors' Families in the Interview	No. of Mentions by the Interviewees
Speculation that the donor was willing to donate before his/her death	12	27
Gossip about organ trading	30	48
Television propaganda	18	30
Talking to someone known with an organ donation	7	12
Organ donation is a good thing	28	47
Organ donation is a continuation of life	26	44
Organ donation is a type of comfort	26	45
Communication with family members	30	46
Concept of the intact corpse	22	31
Trust in the physicians	19	31
Recognition of the work of the coordinator	28	39
Trust in the Red Cross	20	30
Timing of the intervention by the coordinator	14	20
The credibility of the organization	12	14
Improvement in the legal system	11	12
Fairness in organ allocation	5	7
Traditional funeral concept	14	18

## RESULTS

### Demographic Data of the Interviewees

In this study, a total of 30 interviewees participated in official interviews. The demographic data of the interviewees are shown in Table 1. The interviewees were the donors' parent (15; 50%), spouse (9; 30%), brother (3; 10%), or son (3; 10%), including 18 men and 12 women, with a mean age of 41.6 (standard deviation, 10.7) years; rural households accounted for 83.3%; an education level of junior high school and lower accounted for 76.7%.

### Encoding the Results of the Interview Data

The interview notes were analyzed line by line and paragraph by paragraph using the progressive analysis approach, and the data of all of the interviewees were completely input and reviewed with the initial concepts. In this study, the review demanded the use of the local concept of the interviewee for the analysis of the original data to facilitate the in-depth understanding of their opinions and their manner of thinking, thereby providing useful clues for the analysis of the results [4]. Some excerpts from the coding results of the interviews are included below:

"He had said several times before, if possible, he was willing to donate his corneas in the future. Because he had this idea before his death, we should honor his wish." (presumably the donor agreed to donate before his death)

"At that time, after a fierce ideological struggle, we are most afraid of being misunderstood by others to sell his brother's organs." (public opinion pressure)

"In our hometown, if the child is too little, he or she cannot be taken home after his or her death." (traditional funeral concept)

After the coding was performed, a codebook was formed and 17 factors were mentioned, as shown in Table 2. A total of 30 interviewees mentioned that "gossip about organ trading" from neighbors influenced their decision-making, and the number of mentions by the interviewees was 48. A total of 30 interviewees said "communication with family members" was an important factor, and the number of mentions was 46. A total of 28 interviewees mentioned "recognition of the work of the coordinator," and the number of mentions was 39. A total of 26 interviewees mentioned "organ donation is a type of comfort," and "organ donation is a continuation of life," and the numbers of mentions were 45 and 46, respectively. A total of 22 interviewees mentioned "concept of the intact corpse." In addition, many other factors such as "traditional funeral concept" were also mentioned. Thus, firsthand information on the factors that influence the decision-making of the family members of the organ donors was obtained.

### Types of Decision-Making in Organ Donors' Families

Through the interview, we found the decision-making process in the organ donor families can be divided into 2 categories according to the number of people involved in the decision-making: (1) group decision-making, which is again divided into 2 subcategories: (a) all family members participate in the decision-making and reach an agreement; and (b) all immediate family members (spouses, adult children, and parents) participate in the decision-making, with the opinions of other nonimmediate family members being ignored; and (2) individual decision-making, that is, 1 person is the key decision maker who influences others to agree on the donation. Of the 30 cases, 1 case was individual decision-making, 10 cases were the group decision-making in which all family members participate in the decision-making and reach an agreement, and 19 cases were the group decision-making in which all

**Table 3. Framework of Factors That Affect the Decision of the Donors' Families**

Category	Subcategory
Personal factor	(1) Demographic characteristics
	(2) Awareness of organ donation <ul style="list-style-type: none"> <li>• Organ donation is a good thing</li> <li>• Organ donation is a continuation of life</li> <li>• Organ donation is a type of comfort</li> </ul>
	(3) Speculation that the donor was willing to donate before his/her death
	(4) Types of decision-making
Interpersonal factor	(1) Communication among family members
	(2) Professionalism and communication skill of the organ donation coordinator <ul style="list-style-type: none"> <li>• Recognition of the work of the coordinator</li> <li>• Timing of the intervention by the coordinator</li> </ul>
	(3) Talking to someone known with an organ donation
Social and environmental factor	(1) Traditional concept <ul style="list-style-type: none"> <li>• Concept of the intact corpse</li> <li>• Traditional funeral concept</li> </ul>
	(2) Credibility of the organization <ul style="list-style-type: none"> <li>• Credibility of the organization</li> <li>• Improvement in the legal system</li> <li>• Fairness in organ allocation</li> <li>• Trust in the Red Cross</li> <li>• Trust in the physicians</li> </ul>
	(3) Public opinion pressure <ul style="list-style-type: none"> <li>• Gossip about organ trading</li> </ul>
	(4) Propaganda

immediate family members (spouses, adult children, and parents) participate in the decision-making.

#### Generic Analysis of the Factors That Influence the Decision of the Families of Organ Donors

After the repeated comparison, analysis, and classification of the results of the interview data coding, the following 3 categories that affect the decisions of the donor families were obtained: the personal factors, the interpersonal factors, and the social and environmental factors. The personal factors include 4 subcategories, the interpersonal factors include 3 subcategories, and the social and environmental factors include 4 subcategories. Some subcategories also contain finer subclasses. The results are shown in [Table 3](#).

## DISCUSSION

### Impact of the Demographic Factors on the Decision-Making of the Family Members

From the perspective of the demographic data of the donors' families, it may be easier for individuals having no higher education, living in a rural area, and characterized as low-income to present love and dedication. This finding is inconsistent with the results of the related research in foreign studies, which have shown that the population that is

well-educated, of a high socioeconomic status, young, white, healthy, and living in an urban area is more likely to donate organs whereas the organ donation consent rate of people of a low socioeconomic status and with a low educational level is relatively low [5–8]. One study showed temporally interwoven experiences of past, present, and future appeared to influence donor families' decisions [9]. Relevant studies showed that prior knowledge of the patients' wishes were significantly associated with relatives' willingness to donate [10,11]. Relatives' beliefs about the deceased's wishes are the strongest predictor of family decisions [9]. In China, wills are not so common; therefore, in most cases, the wishes of patients are not clear.

### Impact of Traditional Concepts on the Decision-Making of the Family Members

Aiding people or protecting the body of the deceased is an unresolved dilemma for the family members [12]. In China, some inherent traditional thinking of Chinese people may also become constraints to the development of organ donation [13]. The results of this study show that the concept of the traditional funeral, in which the minor is not allowed to be admitted to the ancestral grave after death, was related to the decision-making of the minor donors' families in Hunan Province, particularly in rural areas. The concept of the intact corpse remains an important factor that hindered the families of the organ donors. The families of the donors believed that organ donation is a body-destroying behavior. In the national human organ donation coordinator training session in May 2012, the Tianjin Red Cross reported 70 cases of failure because of the traditional concept of keeping the corpse intact in the families, accounting for 76.9% of the total number of cases; the statistics of Hunan Province showed that cases in which family members opposed organ donation because of traditional concepts accounted for 38.1%. With the development of society and the improvement in the education level of people, the intact body concept is gradually changing [14]. In Hong Kong, the concept of keeping the corpse intact is also the main reason why families refuse to donate; however, this reason has decreased from 49% to 33% [15].

### Impact of the Number of Family Members in Families' Consent

The number of family members is related to the decision-making of the family members. Studies have shown that disagreement among family members is the leading cause of organ donation failure [16]. Duyun Xiao, a contemporary sociologist, reports that "a family is a group consisting of a number of members with a kinship relationship and marriage, including the paternal, maternal, and in-law relatives, forming a relative network system of both parents." In China, particularly in rural areas, for relatively significant events, all family members will participate in the deliberations to jointly make a decision. Compared with adult organ donors, the family structure of minor organ donors is simple, with no relative of the spouse's family, and the number of the family

members is relatively small. Thus, it is easy to reach an agreement in a short period of time. This situation is also reflected in the divorced or widowed families.

#### Impact of the Organ Donation Coordinator on the Families' Consent

Health staff interventions have great influence when the deceased's wishes are unclear; family emotional reactions are related to satisfaction with health staff interventions [9]. In China, the responsibilities of the organ donation coordinator include the following: finding potential organ donors; communicating with the organ donors' families to seek their consent; working on the information registration for the organ donors; coordinating the organ procurement process for the organ donor; providing service for the rehabilitation and recall of the organ donors; providing humane care and assistance to the families of donors; and implementing organ donation propaganda and education. Accordingly, the work of the organ donation coordinator covers the entire process of organ donation, and he or she is the person who is the closest to the donor families [17]. The decision not to consent to donation is attributed to contextual factors, such as feeling overwhelmed by the notification of death immediately followed by the request, not being accustomed to speaking about death, inadequate support from other relatives or health care professionals, and lengthy procedures [18]. Thus, the professionalism of the organ donation coordinator directly affects the donation decision of family members. Special skills of the requester, attention to the circumstances, and unconditional support for the relatives might prevent the relatives' regret about refusal and unnecessary loss of organs [19].

#### Impact of the Credibility of the Organization on the Families' Consent

The environment of the request for the organ donation decision of the family members is important. Whether the family trusts the physicians and nurses can influence the decision of the family. Simpkin et al [20] propose that high-quality care for potential organ donors is an effective measure to reduce the organ donation request rejection rate. Studies also show that the impact of nurses on organ donation is significant; if the nurses lack a correct understanding of organ donation, donor families' attitude toward organ donation will be seriously affected [21,22].

Whether the organ allocation is fair and transparent is a common question of public interest, and it may influence the decision-making of families to a large extent. In a survey of the citizens of Guangzhou, 81% of the interviewees worry about organ trading. The general public does not have trust in the society and the related agencies. They worry that the donated organs cannot be fairly and effectively used and that the donated organs cannot be distributed according to the severity of the disease conditions; they worry that organs may be assigned based on the level of a person's official position, wealth, and fame. In Europe and the United States, a government-appointed special committee or

agency is responsible for the registration and distribution of human organ donations to ensure the fairness and justice of the organ allocation to a certain extent. China has learned from the advanced experience of some foreign countries and has established an organ allocation and sharing system based on internationally accepted principles of organ allocation. Using information technology, the government can expect that the public can supervise and experience fair and transparent processes. However, to be truly fair, the establishment of an open and transparent supervision system is also necessary.

#### CONCLUSION

Factors influencing the families' decision-making for organ donation are analyzed preliminarily in this study, which can be divided into 3 categories including personal factors, interpersonal factors, and the social and environmental factors. The 3 categories contain 11 subcategories and finer subclasses. All these factors affect family decision-making and willingness to donate organs in China.

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