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## **Renal Data from Asia–Africa**

### **Knowledge and Attitude toward Organ Donation among People in Lanja: A Rural Town in India**

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**ABSTRACT.** Organ shortage is the greatest challenge facing the field of organ transplantation today. We aimed to study the attitude and knowledge toward body and organ donation among people in rural India. The present study was conducted in a rural town called Lanja, in the Konkan region of Maharashtra in India. A questionnaire covering demographic data, knowledge, and attitude of the participants was distributed to 400 students, middle-aged and senior citizens; 91.5% of the respondents were aware about organ donation. Television (55.2%) and newspaper (45.8%) were the most popular sources of information. About 56.2% and 32.8% believed that a healthy person and a cardiac dead person can be donors, respectively. Nearly 29.4% believed that a brain-dead person can be a donor and 22.4% clearly stated as to be having no idea regarding the health status of a donor. Highest awareness was observed regarding eye donation (92%). High awareness was also observed regarding heart, kidney, and liver donations, that is, 71.1%, 61.2%, and 54.2%, respectively. Awareness regarding donation of other tissues and organs was poor. Only 46.8% believed that the family of the deceased person can give consent for organ donation if the donor had not signed the donor card. Awareness regarding both body and organ donation in rural India is high. However, there is lack of understanding regarding the concept of brain-death. Awareness regarding body and other organ and tissue donations besides eye, kidney, etc., needs further awareness drives.

#### **Introduction**

These days, transplantation of cornea, kidney, liver, and many other organs are being carried

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out. However, the basic material needed for any transplant is a healthy organ which can be transplanted.

Organ shortage is the greatest challenge facing the field of organ transplantation today.<sup>1</sup> Awareness of organ donation has been found to be directly proportional to level of education.<sup>2</sup>

Denial of brain-death, belief in miracles, religious beliefs, and fear of organ trade were some of the reasons for families to refuse to donate organs of the deceased person.<sup>3</sup>

Residence in urban or rural areas also affects willingness to donate organs.<sup>4</sup>

The present study was carried out to assess the knowledge and attitude of people from a rural part of India regarding organ donation.

### Subjects and Methods

The present study was conducted in a rural town called Lanja, in the Konkan region of Maharashtra in India after obtaining prior ethical committee permission.

In this cross-sectional study, 400 questionnaires were distributed to students, middle-aged, and senior citizens. The students were approached in College, senior citizens at senior citizen clubs called "Jyeshtha Nagrik Sangh" and at Pensioner's Association.

A specially designed self-administered questionnaire covering demographic data, knowledge, and attitude of the participants was prepared and was pilot tested on 30 random persons from Lanja. They were given a period of 15 min for completion of the questionnaire, wherein the respondents would indicate their responses to the questions using the categories provided in the questionnaire in privacy without any discussion with anyone. The questionnaire was thus tested for clarity of the questions as well as time period required for response. Suitable modifications were made in the questionnaire and time span provided.

Table 1. Demographic details of the respondents.

Parameter	Number and percentage of respondents
Persons approached	500
Number of people who consented to participate in study	201
18 to 30 years	124 (61.6%)
31 to 60 years	34 (16.9%)
61 years and above	43 (21.3%)
Marital status	
Married	67 (33.3%)
Unmarried	130 (64.6%)
No comments	4 (1.9%)
Occupation of the Respondents	
Students	124 (61.7%)
Employed	23 (11.4%)
Retired	40 (19.9%)
Homemaker	3 (1.5%)
Unemployed	4 (2.0%)
Refused to divulge occupation details	7 (3.5%)

The methodology was explained to all the participants. The inclusion criterion for the study population was age above 18 years, and exclusion criterion was those who refused to give consent. Only those consenting to participate were involved in the study. The respondents were assured that their confidentiality would be maintained and ethical principles would be followed.

The pretested questionnaire was prepared in Marathi which is a language spoken in this region of India. The option of questionnaire in English was provided to the respondents, who were given a choice of language according to their comfort level. One of the researchers always stood by the respondents to explain any terms in the questionnaire that they had difficulty in understanding. All explanations were made without influencing the respondents.

After the filled questionnaire was collected, information regarding organ donation was imparted in the form of a Powerpoint presentation and discussion session.

### Results

The questionnaire was completed by respondents. The demographic details of the willing respondents are given in Table 1.

Highest percentage (88.6%) of respondents were followers of Hinduism, very few of Islam (3%), and other religious faiths (6.5%). While

Table 2. Awareness of the respondents about organ donation and sources from where the respondents claimed to have obtained the knowledge.

Parameter	Number and percentage of respondents
Awareness regarding organ donation	
Aware	184 (91.5%)
Not aware	11 (5.5%)
Blank	6 (2.9%)
Source of information	
Newspaper	92 (45.8%)
Television	111 (55.2%)
Radio	30 (14.9%)
Internet	45 (22.4%)
Family	28 (13.9%)
Others	
Schools and Colleges	7 (3.5%)
Doctors/ Medical care professionals	6 (3%)

Note: Many respondents claimed more than one source of information.

34.8% of the respondents were educated till std 12<sup>th</sup>, 39.8% were graduates having completed 10 + 2 + 3 years of education. A further 12.5% were postgraduates or in the process of completing their postgraduation. Thus, 87.1% of respondents were moderately or well educated. The highest percentage (61.7%) of respondents consenting to participate in the study was found to be students. Among those who consented to participate in the study, the percentage of retired individuals (19.9%) was found to be higher compared to those who were employed or involved in earning a living (11.4%).

Table 2 depicts the percentage of respondents

having awareness regarding body and organ donation and the sources from where this information was obtained. About 91.5% of the respondents were aware about organ donation and transplantation. Television (TV) (55.2%) and newspaper (45.8%) were found to be the most common sources of information on organ donation. Educational institutes and medical care professionals (3.5% and 3%, respectively) were sources suggested by the respondents as being effective in dissemination of information on body and organ donation.

Table 3 depicts the knowledge of the respondents regarding the health status of the donor. Highest percentage (56.2%) believed that a

Table 3. Awareness regarding health status of the donor and aspects of brain-death.

Parameter	Number and percentage of respondents
Awareness about the health status of a donor	
An healthy person	113 (56.2%)
A cardiac dead person	66 (32.8%)
A brain-dead person	59 (29.4%)
Don't know	45 (22.4%)
Acceptance of concept of brain-death: Would accept a brain-dead person with a beating heart as a legally dead person	
Yes	28 (13.9%)
No	146 (72.6%)
Don't know	24 (11.9%)
Awareness regarding aspects of brain-death	
Brain recovery impossible	91 (45.3%)
Heart is kept beating due to the ventilator	55 (27.4%)
Body feels warm	22 (10.9%)
Person is legally dead	31 (15.4%)

healthy person can be a donor, while 32.8% believed that a cardiac dead person can be a donor. Only 29.4% believed that a brain-dead person can be a donor while 22.4% clearly stated having no idea regarding the health status of a donor. Regarding the understanding of the respondents about “brain-death,” it was found that 72.6% did not believe that “a person who was declared brain-dead but had a beating heart” was actually dead. About 45.3% of the respondents believed that it was possible to recover from brain-death and only 15.4% understood that a person declared as brain-dead was legally dead.

Figure 1 depicts the awareness of the respondents regarding donation of different organs and tissues. Highest awareness was observed regarding eye donation, (92%). High awareness was also observed regarding heart, kidney, and liver donations, that is, 71.1%, 61.2%, and 54.2%, respectively. Awareness regarding body donation and other organ and tissue donations ranged between 21% and 40%.

46.8% of persons believed that a person can be an organ donor even if he/she has not signed the donor card before death and an almost equal percentage (45.3%) believed that unless donor card had been signed before time of death by the potential donor, organ donation cannot be carried out. Nearly 86.1% were aware that a single donor can donate to multiple recipients and save multiple lives.

83.6% believed that donating body/organs is the social responsibility of every individual while 16.4% clearly did not believe so. 32.8% of respondents were unaware that there is a legislation related to organ or body donation.

22.9% believed that a law should be made in India, wherein everyone is an organ donor unless they specifically opt out of organ donation. 46.8% were willing to accept an organ donated by a death row prisoner and 30.3% wanted financial aid to be provided to donor or his/her family members. 91% wanted to be part of an organ donation awareness group and motivate others for organ donation if such an activity was started within their city.

Table 4 depicts results of the study of attitudes of the people, the willingness of the respondents to be organ donors and the reasons for or against organ donation. Among those who were willing to donate, 72.1% were willing to donate to anybody, 13.9% to their own family members, and 6% to their own friends. 11.9% were willing to donate their bodies to the closest medical college.

### Discussion

In a study carried out in the urban population in the state of Maharashtra by Bharambe et al, 78% of the respondents were aware of the concept of organ donation.<sup>5</sup> Alghanim carried out a study to determine whether knowledge

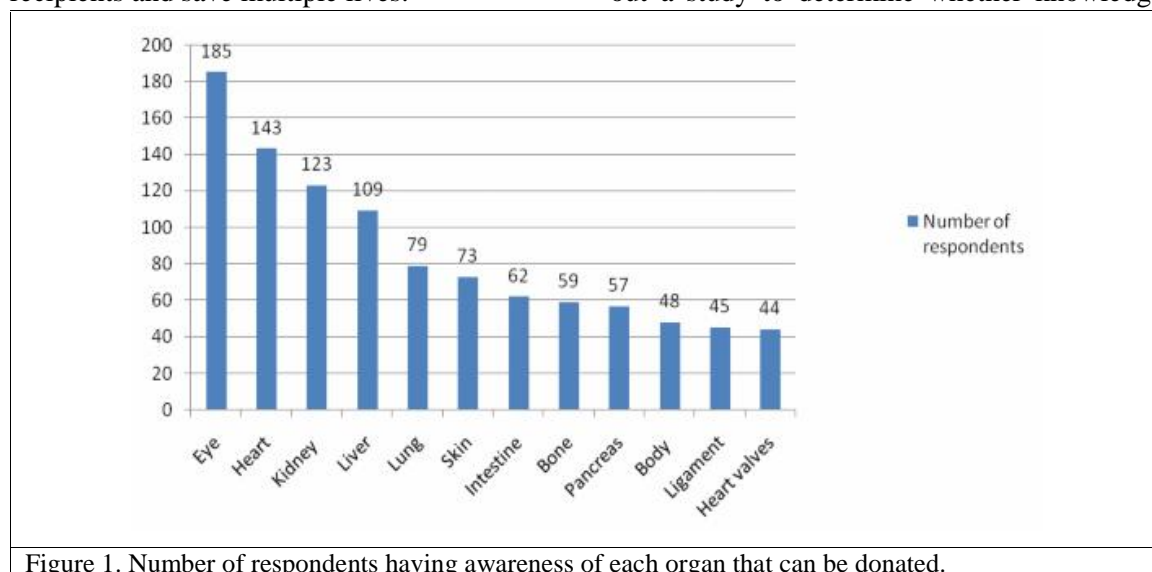


Figure 1. Number of respondents having awareness of each organ that can be donated.

Table 4. Willingness to be an organ donor and the reasons for the same.

Parameter	Number and percentage of respondents
Willingness to be an organ or body donor	
Yes	148 (73.6%)
No	3 (1.5%)
Would like to discuss with family	52 (25.9%)
Don't know	9 (4.5%)
Reasons for being in favor of organ donation	
Something good should come out of my death	106 (52.7%)
I can help someone else live a long and healthy life	66 (32.8%)
I can remain alive even after my death	61 (30.3%)
My religion supports organ donation	15 (7.5%)
Reasons for not being in favor of organ donation	
It is against my religious beliefs	10 (5.0%)
I do not believe in organ donation	4 (2.0%)
I do not wish to be cut open or otherwise mutilated	4 (2.0%)
I do not believe in the ability of the system to support the donated organs till they reach a suitable donor	7 (3.5%)
I fear that the donated organ may be misused	65 (32.3%)
I live very far away from closest center of organ donation	12 (6.0%)
I have fear of the process	3 (1.5%)
I could not be bothered to do all this	7 (3.5%)

and attitude toward organ donation differ between urban and rural population and found that the rural population had less knowledge about organ donation than their counterparts in the urban areas, while in the present study, the rural population was found to have a better knowledge compared that of the urban population in a similar study.<sup>4</sup>

Regarding sources of knowledge, TV (55.2%) and newspaper (45.8%) were found to be the most popular sources of information in the present study. In a study by Khan et al, carried out in Faisalabad, it was found that 46.5% of the respondents claimed to have obtained their information from TV.<sup>6</sup> Alghanim found that 90% of the respondents of urban and rural populations reported that contribution of health-care providers as source of information was "none" or "little."<sup>4</sup> In fact, majority of respondents reported lack of information regarding organ donation. In the present study, the respondents insisted on specially noting the contribution of both medical care professionals and special lectures taken in schools and colleges for increasing awareness regarding organ donation. In a study by Nekar et al, regarding awareness about eye donation, 61.3%

reported media to be their source of knowledge.<sup>7</sup>

Bapat et al also reported newspaper and TV being responsible for 60% of the knowledge propagation.<sup>8</sup> A study by Movius et al, stresses on the role of media as an effective channel to convey important health-related information to the masses.<sup>9</sup> Thus, media seems to be able to reach into the interior of the nation to propagate knowledge regarding organ and body donation. At the same time, the respondents in the present study insisted on emphatically writing down in the questionnaires (in the space provided for comments), the roles of health-care providers and school and colleges as propagators of knowledge. Tontus et al, state that the health-care professionals should be most educated in the field of any kind of organ donation as they are the first persons to set up a relationship with the public, potential donor, or donor family.<sup>10</sup> Thus, they are a decisive link in the process of organ donation. The emphatic insistence of the respondents from the present study, in including the health-care professionals as well as the school and colleges as sources of information underscores the importance of these individuals and insti-

tutions as educators of the public mind. Thus, while media seems to be carrying out an effective role in bringing about awareness regarding organ donation, the health-care professionals and schools and colleges represent less used but important sources of informing the people about organ donation.

56.2% of the respondents believed that to be a donor, one should be healthy. This reflects the awareness regarding living organ donations such as that of kidney. 32.8% believed that a cardiac dead person can be a donor, which is also true since eye and body donations are conducted following cardiac death. However, only 29.4% believed that a brain-dead person can be a donor. Thus, awareness regarding brain-death was poor in the respondents. In a study conducted by Wig et al, involving children, office goers and villagers, it was found that awareness about brain-death was 60%, 81%, and 11%, respectively. They reported that poor awareness regarding brain-death status among villagers was being very alarming.<sup>11</sup>

In our study, only 22% to 40% of the respondents were aware that all other types of organs and tissues such as skin, intestine, and bone, can be donated. In a study carried out by Ronanki et al, in Srikakulam district of South India, awareness regarding eye donation was found to be 93% while in a similar study in another city in South India carried out by Brinda et al, the awareness was found to be 50.7%.<sup>12,13</sup> In a study by Annadurai et al, carried out among college students of Chennai in Tamil Nadu awareness about kidney, heart, eyes, and liver donation was found to be 84.5%, 12.7%, 94.3%, and 1.08%, respectively.<sup>14</sup> In a similar study carried out by Mithra et al, in a southern coastal area, awareness regarding eye, kidney, liver, and heart donations were found to be 99.5%, 98.1%, 45.3%, and 52.3%, respectively.<sup>15</sup> Thus, in three studies, it is observed that above 90% of the respondents were aware of eye donation. In the study conducted by Brinda et al, the awareness was 50.7%. Both these studies from South India indicate higher awareness regarding kidney donation (84.5% and 98.1%) compared to the

awareness in rural Lanja (61.2%).<sup>13</sup> Similarly, on comparing the awareness regarding liver and heart donations, there was variability among the respondents in the different areas. There is need for carrying out awareness programs that give consistent information to the people and raises awareness regarding all forms of organ donation. The awareness regarding the donation of eyes and kidneys seems to be high compared to that of liver and heart.

46.8% of the respondents in the present study were aware that even if a person has not signed the donor card before his/her death, organ donation can be carried out with the consent of the family members. According to the Transplantation of Human Organs (THO) act 1994 and the amendment in 2011, a close family member can take the decision to donate the organs on behalf of the deceased donor.<sup>16,17</sup> It is of utmost importance that this is communicated to the people.

32.8% of the respondents were unaware that there was a law controlling the organ donation and transplant activity. India has a history of organ trade. Purchase of kidneys has occurred for more than a decade often as a result of misuse of the economic status of the donor. To prevent such sale of organs, the THO act was enunciated in 1994 by the Government of India.<sup>16</sup> This law banned the sale of organs and insisted on formation of an authorization committee in the region of all transplant centers to review the potential living unrelated donations.<sup>18</sup> The THO act also provides for punishment to the persons found guilty of conducting, participating, or supporting organ trade in any possible way.<sup>16</sup> Awareness regarding the THO act and its different aspects may go a long way in assuring the public and increase their trust in the activity of organ donation and transplant.

30.3% of respondents believed that financial aid should be provided to the donor or his/her family. This is against the basic doctrine that states that organ donation is a purely altruistic activity.<sup>16</sup> However, Cameron and Hoffenburg have stated that ethical debate is needed on this issue.<sup>19</sup> They provide a counter argument for the theory of altruism-based organ dona-



tion by stating that in an era where capitalist commercialism dominates our thinking, altruism alone has failed to provide us with enough organs, and hence, there is pressure to explore other avenues. The Government of Iran has been paying all its kidney donors officially and is the only country with no patient on the waiting list.<sup>20</sup>

In conclusion, the attitude of the respondents in the rural population of Lanja toward organ donation was found to be positive, with 73.6% being ready to be organ donors. Greater emphasis should be laid on spreading awareness and understanding of the concept of brain-death and organ donation.

**Conflict of interest:** None declared

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