

Why are we Poor Organ Donors: A Survey Focusing on Attitudes of the Lay Public From Northern India

Rajesh Panwar^{*}, Sujoy Pal^{*}, Nihar R. Dash^{*}, Peush Sahni^{*}, Aarti Vij[†], Mahesh C. Misra[‡]

^{*}Department of Gastrointestinal Surgery & Liver Transplantation, All India Institute of Medical Sciences, New Delhi, India, [†]Organ Retrieval & Banking Organization, All India Institute of Medical Sciences, New Delhi, India and [‡]Department of Surgical Disciplines, All India Institute of Medical Sciences, New Delhi, India

Background: Knowledge, sociocultural views, and awareness about organ donation in the general population are important for the success of deceased organ donation. There is an urgent need to gather this information in order to find out the reasons for poor organ donation rates in India. **Methods:** A 30-item questionnaire was designed in the English and Hindi language and was administered to the lay people in order to assess their knowledge, views, and attitude regarding brain death and organ donation. **Results:** Three hundred and fifty-two people (male: female = 202:150; mean age = 30.6 ± 13.9 years) completed the questionnaire. Only 70% of the people were aware that the organs can be donated after brain death and only 44% thought that they understood the meaning of brain death. Media and Internet were the preferred sources for seeking information on brain death and organ donation. The majority of people (81.2%) were willing to donate organs after brain death but only 1.4% had registered for organ donation. Lack of awareness (80.1%), religious beliefs and superstitions (63.4%), and lack of faith in the healthcare system (40.3%) were believed to be the most important reasons for poor deceased organ donation rates in India. The survey also highlighted the importance of the opinion of family members and the religious leaders in making the decision for organ donation. Educational qualification above matriculation was significantly associated with the knowledge of brain death and the willingness for organ donation. **Conclusion:** Lack of awareness appears to be the most important factor for low donation rates in India. Educating people by using media and Internet and conducting awareness programs may help in improving the donation rates. (J CLIN EXP HEPATOL 2016;6:81–86)

See editorial on page 79

Organ donation is a noble act that shows our concern toward fellow human beings who are desperately in need of those organs. In an ideal situation, organ donation is an act of altruism on the part of donor and there should be no other motives attached to it. Indian culture takes pride in moral values like charity and self-sacrifice. This is depicted by a well known mythological story of the sage 'Dadhichi,' who donated his bones for making weapons in order to help the Gods to defeat the demons and reclaim the heaven.¹

Keywords: brain death, deceased organ donation, transplantation, survey, donation rates

Received: 20.01.2016; **Accepted:** 22.04.2016; **Available online:** 30 April 2016
Address for correspondence: Rajesh Panwar, Room No. 1007, Department of Gastrointestinal Surgery & Liver Transplantation, Academic Block, All India Institute of Medical Sciences, Ansari Nagar, New Delhi 110029, Delhi, India. Tel.: +91 1126593461; fax: +91 1126588663.

E-mail: rajeshpanwar81@gmail.com

Abbreviations: NOTTO: National Organ & Tissue Transplant Organization; OPD: outpatient department
<http://dx.doi.org/10.1016/j.jceh.2016.04.001>

In another mythological tale, King Shibi donated his own flesh to a hawk in order to save the life of a dove.¹ King Shibi also offered both his eyes for the restoration of a blind man's sight.¹ These and numerous other examples show that Indian culture and values support organ donation, and therefore, majority of people should be willing for organ donation. But the actual organ donation rates of 0.16 per million population in India are abysmally low as compared to America's 26 and Spain's 35.² Given the large number of fatalities related to road traffic accidents, there is huge potential for deceased organ donation in India and it has been estimated that organ requirement would be met even if only 5–10% of potential donors become actual donors.³ The organ donors come from the society and the knowledge, sociocultural views, and awareness about organ donation among various population groups in society shape the attitudes of people toward the concepts of brain death and deceased organ donation. Thus, the information on the knowledge, attitudes, and practices of people with regard to deceased organ donation is very important; but only a few studies^{4–7} have addressed this issue. This study aimed to assess the awareness of the brain death and the concept of deceased organ donation among lay people and to identify the potential reasons for the low rates of deceased organ donation.

METHODS

The study was conducted from July 2012 to January 2014 in the department of Gastrointestinal Surgery and Liver Transplantation, All India Institute of Medical Sciences, New Delhi. The study was approved by the Institute's Ethics Committee. A questionnaire was designed to assess the awareness and attitude of the general population regarding brain death and organ donation. The questionnaire was designed in Hindi (Annexure I) as well as in the English (Annexure II) language. The questionnaire was initially administered to 10 lay people as a trial and suggestions were invited. Based on these suggestions, further changes were made and the questionnaire was finalized. The final questionnaire consisted of thirty questions and included yes/no based and multiple response based questions. Some multiple response questions allowed selection of a single response while others allowed selection of multiple responses. The questionnaire also required demographic details like age, gender, religion, and educational status. A single male investigator (RP) administered the questionnaire to the target population. After an initial introduction, the participants were explained about the purpose of the study and were asked to complete the questionnaire if they consented for the same. The investigator clarified the general queries of the participants and also explained the meaning of the questions if they had any problem in understanding them. However, the specific information that could have an impact on questionnaire responses was withheld and participants were told that they could clarify all their queries after completing the questionnaire. Participants who could read and write were encouraged to fill up the questionnaire themselves. The investigator read out and explained the questions to the illiterate participants and marked the responses selected by them. The inclusion criterion was the ability to understand the questionnaire in either language (Hindi and English). We did not exclude any person on the basis of religion or caste. Hence, children below the age of 12 years, those who could not understand either English or Hindi, or those who said that they did not understand the questions being asked were the only exclusions. The participants for the survey were chosen as follows:

- a) The people attending the health exhibitions and public lectures organized at All India Institute of Medical Sciences, New Delhi from time to time. These include school and college students, teachers, and local residents.
- b) The people accompanying patients visiting the outpatient department (OPD).

Statistical analysis was done using Statistical Package for the Social Sciences (version 17.0; SPSS Inc., Chicago, IL, USA). Responses for each question were expressed as percentage. A chi-square test was used for the comparison of qualitative data and a *P* value <0.05 was considered significant.

RESULTS

The questionnaire was administered to 400 lay people, who included patients' relatives attending the OPD, people attending scientific/health exhibitions, school children, college students, and teachers. Of these, 48 incomplete questionnaires were rejected. Thus, 352 questionnaires were available for analysis. There were 202 male and 150 female respondents. The mean age of respondents was 30.6 ± 13.9 years; majority of them were Hindus and around half were diploma holders/graduates/postgraduates (Table 1).

Out of all the people included in the survey, 85.5% were in the age group of 15–49 years and 98.9% were literate. However, according to the population data from 2011 census, only 58.7% of people in Delhi were in the age group of 15–49 years and the literacy rate was only 86.2%.⁸

Most respondents were aware that transplantation may benefit patients suffering from organ failure (93.5%) and that there is shortage of donated organs (96%), while only 69.3% were aware that the organs could be donated after brain death. More people were aware about eye (85.8%) and kidney (83.5%) donation as compared to other organs like liver (77.0%), heart (66.8%), lungs (56.0%), heart valves (55.1%), and bones (50%). Only 44% of lay people were confident about their knowledge and understanding of brain death and majority of them had received this information from media (41.2%) and Internet (24.4%). Media (31.3%) and Internet (35.5%) were also the preferred sources for seeking such information in future.

Only 56.8% of lay people had seen a poster regarding organ donation. Only around 10% of respondents had known anybody who required or had undergone a transplant. Most people (82.6%) were willing to accept an organ from a deceased donor for their relative. Only 55.1% of lay people were aware about donor cards and donor registration and only 1.4% had registered themselves as organ donors, but 71% were willing to apply for it. Majority of people (81.2%) were willing to donate organs after brain death.

Lack of faith in healthcare system (42.9%), religious beliefs (41.7%), and fear of disfigurement (35.7%) were the most common reasons for not donating organs among the people who were not willing to donate organs. Most people (88.4%) thought that views of the family are important in decisions regarding organ donation and 40.9% of people would change their decision for organ donation if it was not supported by their family. Around 37% of respondents wanted to know or were influenced by the opinion of their religious authority/spiritual guru in deciding about organ donation.

Most respondents (72.4%) believed donor willingness to be the most important factor in deciding organ donation. In case donor willingness was not known, 44.9% of people felt that the decision should be made by the next of kin and only 14.8% thought that hospital authorities should be

Download English Version:

<https://daneshyari.com/en/article/3338434>

Download Persian Version:

<https://daneshyari.com/article/3338434>

[Daneshyari.com](https://daneshyari.com)