Original Article

Did an Increase in Knowledge and Awareness about Organ Donation Improve Organ Donation Rate in India Over the Past Two Decades?

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Abstract

Context: The growth in the solid organ transplant has not been able to keep pace with the global requirement for organs, with great differences among countries. No previous studies about public awareness related to organ donation over two-decades have been conducted. Aim: The paper focuses on studying the difference in the knowledge and attitude among the Indian public about organ donation, over two decades. The study further probes into the impact that public knowledge has on organ donation rates. Settings and Design: This is a cross-sectional study conducted from 1998 to 2017. The first 10 years of the study (Group-I) was administered physically, whereas in the next 10 years (Group-II) online tools were used to conduct the survey. The total number of respondents in the two decades was 3914. Subjects and Methods: It contained a structured questionnaire with ten multiple choice questions and basic demographic details. The survey questions were the same for both the periods of the study. Statistical Analysis Used: The data entered was analyzed using SPSS v. 19. The knowledge on organ donation was compared between the two decades and if in any increase in awareness was reflected in the organ donation rate. Results: The increase in awareness on the organs and tissues that can be donated was high among Group-II and it was statistically significant (P < 0.001). More importantly, the proportion of respondents who were aware about the "organ donor card" more than doubled from 23.7% in Group I to 63.7% in Group II; and this was statistically significant (P < 0.001). The deceased donation rate was 0.08 per million population in 2004, whereas it had increased to 0.34 pmp in 2014 and 0.8 pmp in 2016. Conclusions: There has been an increase in awareness in the two decades, and this is also reflected in an increase in the donation rate in the country. Creating more awareness can be one of the factors to increase the organ donation rate in India.

Keywords: Brain death, donor card, knowledge, organ donation, organ transplantation, public attitude, public awareness

INTRODUCTION

The solution for irreversible organ failure is organ transplantation. The advancements in the organ transplantation have meant better graft outcomes and patient survival after transplantation. [1-5] However, this growth has also meant an increase in waiting lists of patients requiring transplants due to a shortage of organ donors. [6,7] When a body is cremated or buried most organs are wasted without much thought that the same organs could have saved lives. This phenomenon is akin to "scarcity" in "abundance." [8] This scarcity could be overcome if there were more people in the society who would be willing to donate their organs by either signing up through an organ donor registry or through a donor card and having a conversation with their family members about their desire

to donate organs. Success of the organ donation program depends on awareness about issues related to organ donation in the society and the willingness of the people to decide to donate organs. Hence, sensitization about issues related to donation after death is important for improving the donation rate in the society.^[9]

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India passed the law entitled Transplantation of Human Organs Act in 1995 and accepted brain death as a form of death and made organ transplantation from deceased donors possible. It also made organ commerce a punishable offense. [10] However, it has had an abysmally low deceased donation rate due to various factors primarily among them includes the lack of awareness regarding issues related to brain death and organ donation, diversity in healthcare delivery, and lack of access to tertiary care for a large proportion of the population.[11-16] In the first 10 years after the law was passed the donation rate was 0.08 per million population (pmp) in 2004 and the next 10 years, it saw some gradual increase; in 2016, this increased approximately ten times to 0.8 pmp.^[17,18] What one must remember when such calculations are done is that only 13 of the 35 states and union territories in India contribute to the pool of deceased donors and of these only a few states have made a significant contribution to the success of the program.

SUBJECTS AND METHODS

This cross-sectional study was aimed to assess the general public's knowledge of organ donation. This study used a structured questionnaire with ten multiple choice questions and basic demographic details. The survey was conducted from 1998 to 2017 by a not-for-profit organization. From 1998 to 2007 (Group-I), data were collected through a physical questionnaire before the start of an awareness program in various states and from 2008 to 2017 (Group-II) an online tool was used for data collection. The survey questions were same for both the groups. A total of 3914 individuals responded to this study. In Group-I, there were 1461 respondents of which, 797 were male and 664 were female; whereas in Group-II, there were 2453 respondents with 1532 males and 921 females. The online tool was used to simplify analysis and administered as presurvey before conducting an awareness programme in colleges, clubs, corporate, and through online campaigns for organ donation. Only fully filled forms were used for analysis and incomplete ones were discarded.

The survey also had a secondary objective of a tool to educate the public about issues related to organ donation as a verbal response or online feedback was provided for each of the ten questions on submission of the survey.^[19] However, this was not measured.

The data were entered into Microsoft excel 2010 program and analyzed using SPSS v. 19 IBM Statistical Package of Social Sciences version 19 (IBM, PASW Statistics, India Country office, Bangalore, India).

RESULTS

The respondents were divided into two groups for comparison based on the period of the survey; the first time period from 1998 to 2007 will be henceforth referred to as Group I and the second time period from 2008 to 2017 will be henceforth referred to as Group II.

Among the overall respondents, 2329 (60%) were male and 1585 (40%) were female. Majority of the participants

were below the age of 50 years in both groups. The educational profile changed between the two time periods marginally. The respondents in Group-I predominantly held an undergraduate qualification (63%), whereas in Group-II, 44% of the respondents were an undergraduate. Majority of the respondents (78%) were Hindus in both the Groups [Table 1].

A higher proportion of the study participants in Group-II responded that all organs can be donated compared to Group-I. The increase in awareness for all the organs that can be donated was statistically significant (P < 0.001) [Figure 1].

Only 2% of the surveyed population were unaware about organ donation, and there has been no decrease over time. The awareness regarding when a person could donate their organs was similar in both the groups.

There was an increase in the number of respondents from 58% in Group-I to 61% in Group-II, who were aware that organs could not be sold and this was statistically significant (P = 0.001). Awareness on the concept of brain death and the Indian parliamentary law recognizing brain death as a form of death that allows organ donation to those in need was higher in Group-II (83% and 74%) as compared to that of Group-I (66% and 45%), and they were statistically significant (P = 0.001). Of all the respondents who took the survey in Group-II, 81% said that as for the next of kin they were willing to consider organ donation of a relative in the event of brain death compared to 69% of the respondents in Group-I. More importantly the proportion of respondents who were aware of the "organ donor card," more than doubled from 24% in Group-I to 64% in Group-II; and the increase was statistically significant (P < 0.001). More than 90% of the overall respondents said that they are willing to consider

Table 1: Gender, age, education, and religious distribution of the respondents (n=3914; Group 1 [n_1]=1461 [1998-2007]; Group 2 [n_2]=2453 [2008-2017])

	Group I, <i>n</i> ₁ (%)	Group II, <i>n</i> ₂ (%)	Overall, <i>n</i> (%)	
Gender				
Male	797 (55)	1532 (63)	2329 (60)	
Female	664 (45)	921 (37)	1585 (40)	
Age (years)				
<25	848 (58)	1061 (43)	1909 (49)	
26-50	609 (41)	1205 (49)	1814 (46)	
>51	4(1)	187 (8)	191 (5)	
Education				
Under graduation	926 (63)	1079 (44)	2005 (51)	
Postgraduation	464 (32)	974 (40)	1438 (37)	
PhD	3 (0.2)	54 (2)	57 (2)	
Others	68 (5)	346 (14)	414 (11)	
Religion				
Hindu	1286 (88)	1769 (72)	3055 (78)	
Christian	135 (9)	244 (10)	379 (10)	
Muslim	11(1)	68 (28)	79 (2)	
Others	29 (2)	58 (2)	87 (2)	
Not willing to reveal	0 (0)	314 (13)	314 (8)	

carrying an organ donor card and express their desire for organ donation after death [Table 2].

In 2004, the donation rate was 0.08 per million population (pmp) and the next 10 years, it saw some gradual increase; in 2016, this increased approximately ten times to 0.8 pmp. [17,18] Only a few states have made significant contribution to the success of the program because such calculations are done from only 13 of the 35 states and union territories in India which contributed to the pool of deceased donors.

DISCUSSION

India with 1.21 billion population, [20] has a long way to go in deceased organ donation. In 2004, the donation rate was 0.08

per million population (pmp)* and in the next 10 years, it saw some gradual increase. In 2016 though, the rate increased approximately ten times to 0.8 pmp. [17,18] Tamil Nadu being a model state in this field had an organ donation rate of 2.5 pmp (180 donors) in 2016. [18] The increase in awareness among the public over the two decades collaborates with improvement in the donation rate in the country. Despite such improvement India ranks low among the list of countries with regards to deceased donor transplant rate. [18,21-23]

Various studies have depicted that there is a reasonable amount of awareness on organ/tissue donation in India; [24-27] however, this willingness does not seem to translate into actual organ donations due to various reasons and one among them may be that there is no last mile mechanism in place where all

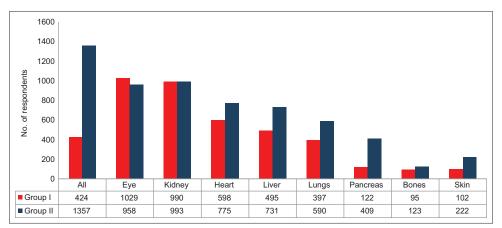


Figure 1: Responses on organs that can be donated (n = 3914; Group I = 1461 [1998–2007]; Group II = 2453 [2008–2017])

Table 2: Association between Group I and Group II on their knowledge and attitude towards organ donation. (Group	I
$[n_1] = 1461 [1998-2007];$ Group II $[n_2] = 2453 [2008-2017])*$	

Questions	Responses	Overall, <i>n</i> (%)	Group I, <i>n</i> ₁ (%)	Group II, n_2 (%)	P*
1. Are you aware that organs can be donated to save a life of another	Yes	3841 (98)	1430 (98)	2411 (98)	0.360
person?	No	73 (2)	31 (2)	42 (2)	
	During life	211 (5)	27 (2)	184 (8)	
2. When can organs be donated?	After death	1122 (29)	452 (31)	670 (27)	0.000
	Both	2581 (66)	982 (67)	1599 (65)	
3. Do you have a relative whose organs have been donated?	Yes	615 (16)	193 (13)	422 (17)	0.001
	No	3299 (84)	1268 (87)	2031 (83)	
4. Can we sell our organs (like kidney)?	Yes	725 (19)	251 (17)	474 (19)	0.001
	Not sure	852 (21)	365 (25)	487 (20)	
	No	2337 (60)	845 (58)	1492 (61)	
5. Have you heard of brain death?	Yes	3002 (77)	970 (66)	2029 (83)	0.000
	No	912 (23)	491 (34)	424 (17)	
6. As the next of kin, would you be willing to donate the organ (s) of a	Yes	3002 (77)	1014 (69)	1988 (81)	0.000
brain dead relative?	No	912 (23)	447 (31)	465 (19)	
7. Are you aware that a parliamentary law in India recognizes brain	Yes	2467 (63)	660 (45)	1807 (74)	0.000
death as a form of death so that organs like kidneys, heart, liver and lungs can be donated to needy patients?	No	1447 (37)	801 (55)	646 (26)	
8. Do you know what an organ donor card is?	Yes	1908 (49)	346 (24)	1562 (64)	0.000
	No	2006 (51)	1115 (76)	891 (36)	
9. Are you willing to carry an organ donor card and express your desire	Yes	3584 (92)	1309 (90)	2275 (93)	0.000
about organ donation after your death?	No	330 (8)	152 (10)	178 (7)	

^{*}Chi-Square test (referring to the above table)

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families are given an opportunity to either say yes or no to donations at the time of death of their loved ones in a hospital. This has been addressed by the transplantation of human organs (Amendment) Act 2011^[28] and transplantation of human organs and tissue rules, 2014^[29] of the Indian law which makes it mandatory for doctors and transplant coordinators to ask for organs in the event of brain death in the ICU. This is popularly known as a required request.^[8] The last 10 years have seen an increase in donation rates in 13 states and union territories of the country mostly from tier 1 and tier 2 cities. Both print and visual media could have played a key role in improving awareness of organ donation.^[30]

Since health personnel play an important role in the hospitals when they speak to the relatives at the time of death; conducting regular sensitization to the staff and educating them about the required request clause in the law will help to recruit more staff to support the cause and this would ultimately help the public to donate their loved one's organs. [8] The required request has been done with the intent to increase the rate of organ donation and to overcome the critical shortage of transplantable organs.

Educational profile of the population may also be a determinant in decision-making about organ donation. In both the time periods, the profile of people was from the educated class be it undergraduate or postgraduate. Although there was some shift in the educational profile with the number of respondents in the higher education category in Group II, this should not have been a factor in their knowledge or attitude to organ donation.

Age is an important factor for organ donation and organs from younger donors are far better than organs from older donors. [31] In India, most deceased donors are from road traffic accidents and are young males. [32-34] The survey also represents predominantly younger age population and has more male respondents compared to females. Agrawal *et al.* [35] in 2017 conducted a study which showcased majority of the respondents (78%) were below the age of 35 years. On similar lines, in this study, 99% of the respondents were <50 years.

The main focus of organ donation is to save lives; which was clear in the mind of the respondents as 98% agreed that organ donation could save the life of another person and there was not much difference between both the groups. These findings were similar to a study conducted by Annadurai *et al.* [36] in 2012, where all the respondents were aware that organ donation save lives. Group II had a statistically significant number of respondents on the awareness that all organs can be donated (P < 0.001). The number of respondents in Group II was lower for eyes and kidney; this could have attributed to the higher proportion of respondents who were aware that all organs can be donated.

Studies prove that awareness on organ donation and transplantation has increased following awareness campaigns^[30,37] and media reports in recent years. A study conducted by Naveen *et al.*^[38] in 2014, presented that most of the respondents were aware of kidney and cornea donation

while there was not much awareness of skin, pancreas, bone, and lung donation.

Concerning the attitude toward organ donation, this study exhibited that majority which was 69% and 81% of the respondents from Group I and Group II, respectively, expressed their willingness to donate the organs of their next of kin after brain death. This increase in willingness as pointed out earlier could be attributed to the positive stories in the media about organ donation and the success of organ transplantations.^[30,39-41] This observation was similar to a study conducted by Mithra *et al.*^[42] in 2013 where 83.2% of the respondents were willing to donate the organs of a brain-dead relative.

There is a gradual increase in the number of respondents who are against the sale of organs from 58% in Group I to 61% in Group II, and this is again statistically significant (P = 0.001). In a study carried out by Josephine's study^[41] done in 2013, 72.7% were against economic benefit of organs and Mithra's *et al.* study^[42] in 2013, 67% of the respondents were against accepting monetary benefits for donating one's organs.

When we look at the awareness on the concept of brain death against the law toward organ donation in Group I (66% and 45%) and Group II (83% and 74%), there was a statistically significant increase in Group II. This serves as an evidence for increase in knowledge toward organ donation. A study conducted by Josephine^[40] in 2013 stated that 56% of the respondents were aware of the legal aspects of organ donation, which shows similar results to the present study. There was an exponential change over the period in this study about the awareness on donor card from 25% in Group I to 64% in Group II which was statistically significant (P < 0.001).

The strength of this study is the 20 years period of the survey as there are no previous studies comparing awareness between the two decades of the time period. The high number of respondents makes this study more sensitive to extrapolate to the population under study. To ensure uniformity for comparison of the two groups, the incomplete questionnaires in the online tool were discarded. The advantage of the online tool was that each response had a stem that educated the respondent if they were unaware of any of the issues and that served as an excellent educational tool, whereas in the physical survey, there were multiple interns undertaking the study and their response may not have been standardized.

The awareness among the general public about organ donation is higher in Group II compared to Group I. Our study observes that there has been an increase in public's awareness on issues related to deceased donation in the two decades and there is also an improvement in the organ donation rate in the country. However, improvement in the public's awareness is likely to be only one of the many factors for this improvement in the organ donation rate.

The public needs to be educated more on the important aspects of organ donation such as brain death, legal implications in the commercial dealings of organs, and organ donor cards as an expression of one's desire to donate. Since the present generation is proficient in using modern technology, social media should be used as a tool to spread awareness on organ donation. Larger number of female respondents should be included in similar studies as they could be used as peer educators for spreading awareness among the public.^[43]

CONCLUSION

The survey looks at the difference in knowledge and attitude among the public about organ donation over two decades. The first is from 1998 to 2007 (Group I) and the second from 2008 to 2017 (Group II). The difference as observed reflects a rise in the level of awareness on organ donation between the two time periods and corroborates with the increase in donation rate in the country. While it cannot be concluded that awareness is a standalone factor that lead to increase in the organ donation rate, it is evidential that increasing awareness among the public on organ donation can play a significant role in improving the donation rate in the country.

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Conflicts of interest

There are no conflicts of interest.

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