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Original Article

A descriptive study of community-based profile and attitudes of body donors of an urban conglomeration in Western India

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ABSTRACT

Background: Body donation is considered an altruistic act done by people for advancement of science. There has been a significant depreciation in the availability of cadavers for teaching and research all over the world. Unlike India, many countries have studied the profile and attitudes of potential body donors to improve body donation. With a huge health sector, this Indian study studied the profile and attitudes of body donors and their role in aiding science through body donation.

Methods: Four hundred thirty-one survey forms with informed consent were sent to registered body donors. The questionnaire focused on demographic parameters and their perception on body donation. The data were collated, compared and interpreted with similar studies done worldwide.

Results: The study shows an interesting pattern among the Indian donors in comparison to the West. An Indian donor is a male individual in 70s, highly educated and religious with good social background. Despite many similarities, there are important distinguishing features unique to our country and many myths surrounding body donation.

Conclusion: The Indian donor is highly educated male and charitable with strong belief in God. He believes in aiding medical science through body donation.

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Introduction

Body donation is considered an altruistic act done by people for advancement of science,^{1,2} a concept popular in the West for medical research and training. Dissection of cadavers provides the “feel” and spatial anatomical relationships unlike prosections and computerised virtual anatomy. The cadaveric

dissection has been considered as a “rite of passage” for the new student, and he is taught to respect his first “patient”.¹ But in midst of increased healthcare demands and legal restraints, the availability of cadavers was diminishing. This led various workers around the world to study the profile and attitudes of potential body donors and rejuvenate the bequest programmes in their respective institutions. Many surveys have been done in New Zealand, Netherlands, South Africa,

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Ireland, United States, Greece and Brazil,¹⁻⁷ but very limited number of studies are available from South Asian countries. The results from these studies indicated unique trends based on social demographics and opinions of donors and attributes influenced by local customs and traditions of different countries.¹ These studies were very effective to understand and motivate and dispel myths and misconceptions in the community about body donation, and it had been able to alleviate to a large extent the paucity of cadavers for scientific research. Since, similar studies on profile and attitudes of donors have not been done in India; the goal of this study was to understand an Indian donor's opinions, improve donor education and facilitate cadaver availability for medical training and research.

Material and methods

The study conducted was a retrospective cross-sectional survey of profile and attitudes of registered body donors in the Department of Anatomy, of a medical college in Pune from March 2013 to September 2015. The study focussed on qualitative and quantitative analysis of various demographic and socioeconomic data and their interpretation. The design was based on a similar multicentric study done in New Zealand, Ireland and South Africa.¹ The donors belonged to Pune city, a big urban conglomeration in Western India and an important educational and industrial centre. The registered donors had representations from both genders and from various professions. There were no specific exclusion criteria, but donors outside the city limits (Pune rural) were not included in the study. All the respondents had been geographically tagged to their residence addresses (www.easymapmaker.com, Fig 1) in 17 geographical areas for any signs for clustering. The demarcation for "inner" parts of Pune was Vimannagar/

Khadki in the north, Hadapsar in the east, Bibwewadi in the south and Kothrud in the west. The "peths" were considered the central parts of Pune, while areas outside of these were considered "outer" zones. The sample size was estimated using 95% confidence interval for the proportion of study population having knowledge about various aspects of body donation with 5% absolute error of margin. The sample size of 385 was found adequate if it was assumed that 50% of study population has adequate knowledge of various aspects of body donation. However, 431 registered donors of the defined population were included in the study. The sample may be generalisable to any big urban conglomeration of India. The institutional ethical committee approval was obtained before the survey was initiated.

The registered donors were sent a covering letter, information sheet, consent sheet, anonymous questionnaire and a return self-addressed envelope. The information sheet provided information on voluntary nature of the study, objectives of the survey and assured them of confidentiality and ethical principles. The letters were sent from November 2015 onwards and completed by January 2016. A waiting period of 6 months was chosen for receipt of survey questionnaires. By September 2016, the survey information was collated, and the data were extracted. An effort was made to contact the registered donors by telephone who had not submitted the survey, and duplicate sheets were sent in case of difficulties or change of address. By April 2017, the survey endpoint was reached and formal assessment of the questionnaire commenced. The questionnaire included queries on age, gender, marital status, occupation, sources of information, programme awareness, reasons for making the bequest, education, ethnicity, relationship status, occupation, religion, incentives, etc. The questionnaire based on a similar survey by Cornwall et al¹ and Halou et al² was checked for internal validity by the subject experts. The data from the survey were

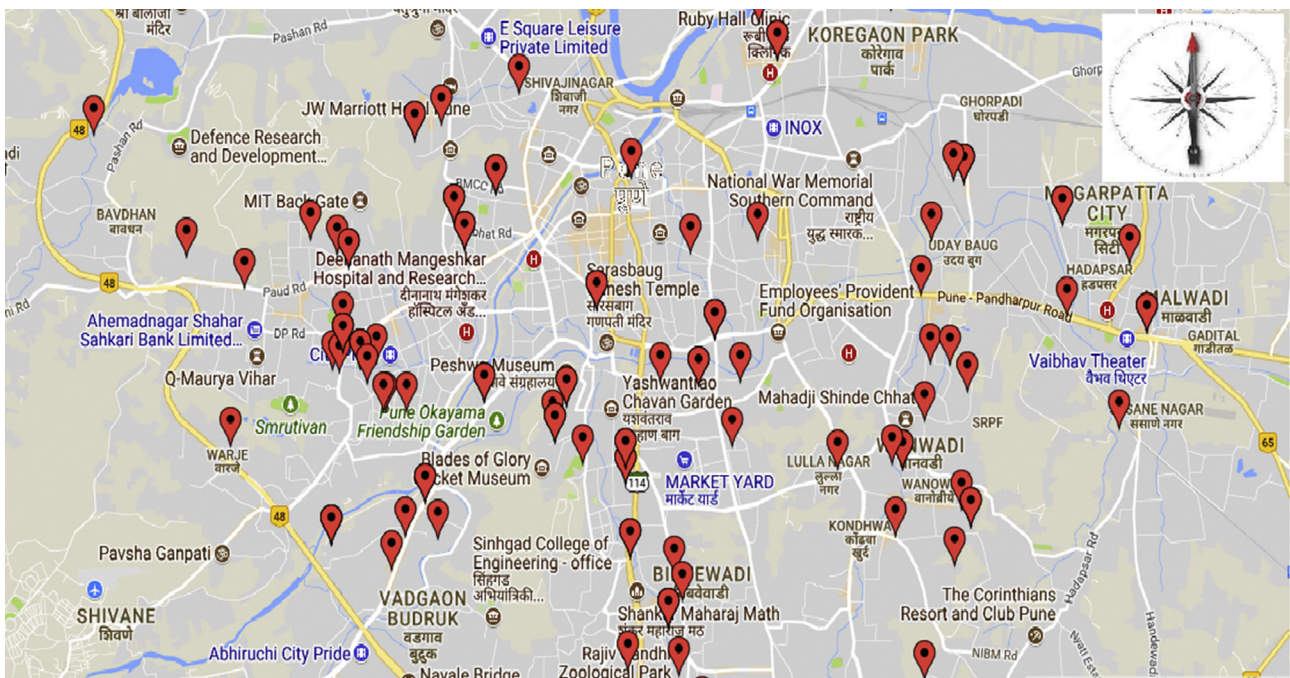


Fig. 1 – The geographical clustering of respondents in the city.

entered into an Excel spreadsheet program (Microsoft, Redmond, WA) for analysis and compared with similar studies done in other parts of the world. The data from the open-ended questions were thematically analysed and presented in table.

Results

Sociodemographic factors

A total of 445 citizens registered for body donation in the department out of which 431 were selected for the survey, and 141 responded. The “others” in the group were excluded from the survey for various reasons (Fig. 2). The number of male individual respondents was markedly more than the female, and couples were the second biggest group (Fig. 3). The median and percentile age distribution amongst the two genders were quite similar with some very young registered participants amongst the males (Fig. 3).

The geographical tagging of the donor addresses revealed comparatively larger clustering from the inner west (Kothrud, $n = 29$) and inner south ($n = 16$) of the city (Fig. 1). The whole of western and southern parts of the city had a total of 66 respondents (46.8%).

In terms of ethnic representation, maximum registrations were recorded from the Hindu community while the Christians and Jains had an equitable distribution in comparison to their demographic status⁸ (Table 1). The registrations from Jews and Zoroastrians were 0.22% and 0.45%, respectively, but they chose not to respond to the survey, while Buddhists had no registrations for body donation.

The majority of respondents ($n = 120$, 85.1%) believed in God (Table 2). There were 111 (78.7%) individual married members, eight (5.77%) were unmarried, and 17 (12%) had lost their spouses. Total registration by spouses of body donors was 68 (48.2%) which included 29 couples. They responded to the survey together while the remaining 10 did it at a later date. The respondents varied in age from 22 to 91 years with maximum representation between 61 and 80 years ($n = 87$,

61.7%). The maximum number of donors ($n = 51$) had two children in their 30s (Table 2).

The potential body donors represented diverse array of occupations before retirement or were still employed. Other than the homemakers, 61 (43.2%) were from management, armed forces and the engineering/information technology streams. People from medical stream constituted only 3.5% ($n = 5$) with only three doctors, rest being paramedical staff. The number of respondents with graduate and postgraduate degrees was 103 (73%). The level of responsibility in their jobs was “high” at 49.6% indicating managerial and executive positions (Table 2).

Profile and attitudes of registered body donors who responded to the survey on body donation

Only 31.9% ($n = 45$) of the respondents accepted easy availability of body donation information from public domain, but 78.6% of them professed their knowledge on donation from friends, families, books and television. In spite of no registrations from family members of 79 (56%) respondents, 42.3% ($n = 86$) of discussions on body donation was done within family members, relatives and wife, while for 15.2% ($n = 31$), it was a self decision. Still, a substantial number ($n = 59$) were unaware of the final disposal of the cadaver. Interestingly, the respondents advised body donation to all except their own children and colleagues. Among the relations of the respondents who had already registered, “fathers” formed the biggest group. 74.5% of respondents were magnanimous with history for charitable donations (Fig. 4).

An overwhelming number of respondents reasoned their desire to donate to “aid medical science” ($n = 128$, 90.7%) and “offer gratitude” ($n = 61$, 43.3%), while a significant number had a dislike for cremation and last rites ($n = 24$). Religious issues (61.7%), superstition (53.9%), family objection (43.2%) and misconceptions were the main reasons why people did not opt for body donation. 39.7% ($n = 56$) of the respondents desired medical care in the institution as a valid incentive, while 25.5% feel otherwise, being a voluntary altruistic act. An overwhelming number (55.3%) of respondents did not answer the

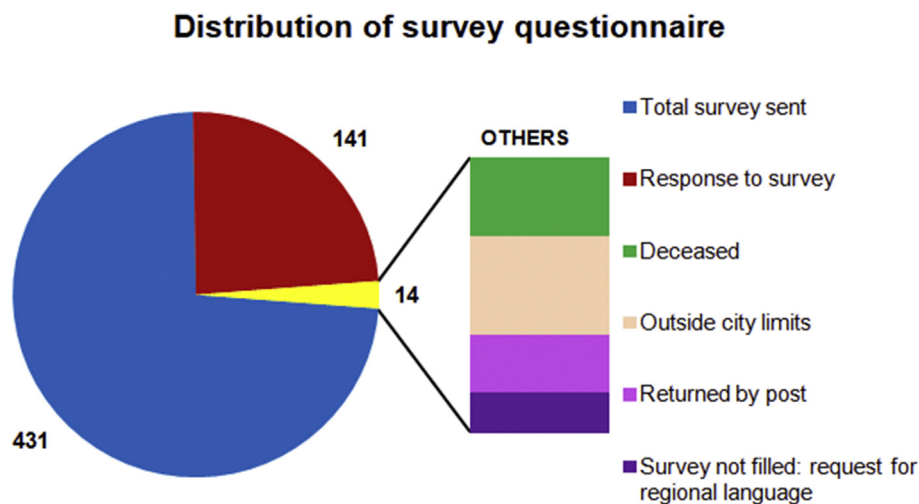


Fig. 2 – Distribution of survey amongst 445 registered donors. The “other” group was specific registered donors who were not included in the survey.

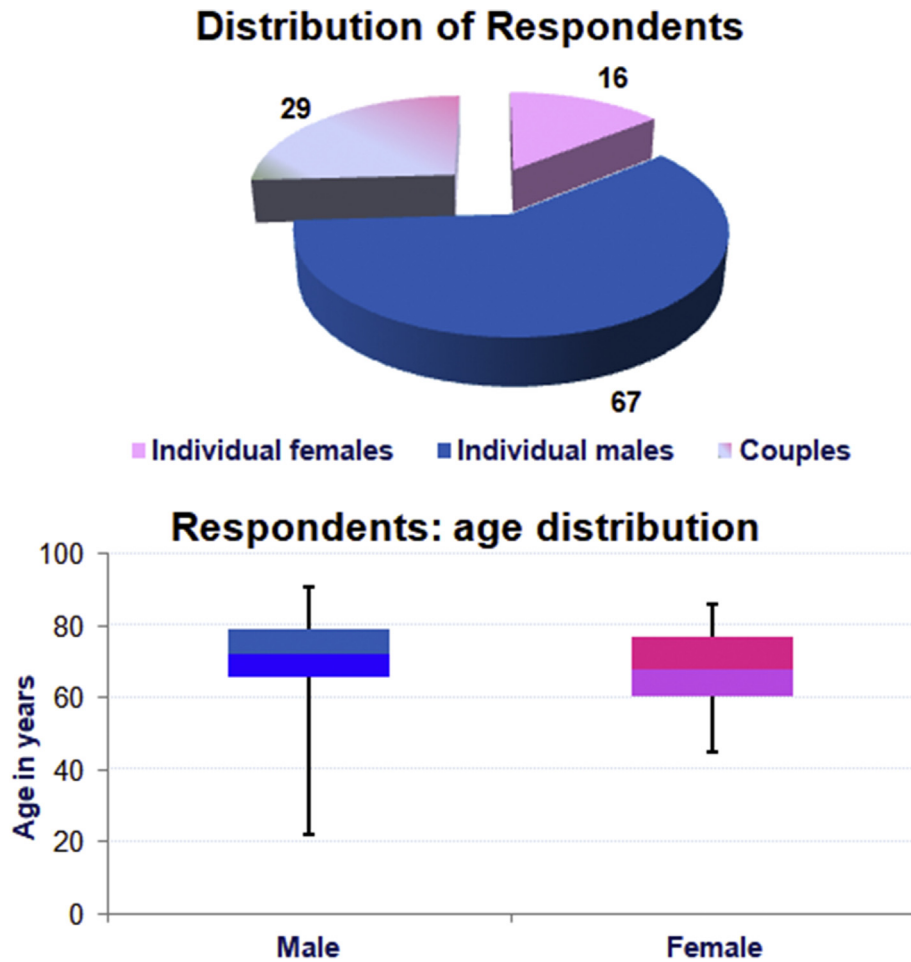


Fig. 3 – Pie chart shows the gender-wise breakup of those who responded to the survey. The box and whisker chart shows the median and percentiles of the respondent’s age distribution.

Table 1 – Showing distribution of faith amongst the respondents and the registered body donors.

Faith	Total no of respondents of survey (a)	Total registered for body donation (b)	Percentage amongst respondents (a × 100/141)	Percentage amongst total registered (b × 100/445)	Census 2011 of Pune # (in %)	Percentage of respondents amongst registered (a × 100/b)
Hinduism	130	415	92.17	93.25	78.8	31.32
Islam	1	4	0.71	0.90	11.3	25
Buddhists	0	0	0	0	4.00	0.00
Jain	4	11	2.84	2.47	2.42	36.36
Christianity	3	10	2.13	2.22	2.37	30
Sikhism	1	2	1.42	0.45	0.52	50
Total	141	445				

query nor had an idea on organ donation (Table 3). Thematic analysis of open-ended question on improving body donation programme revealed people wanted more publicity for body donation with some other relevant feedbacks (Table 4).

Discussion

All registered donors who have responded to the survey are referred as respondents.

Participation in survey and location of respondents

In this study, the participation in the survey from registered donors was 32.7% (Fig. 2), much lower than other studies where it varied from 70 to 76%^{4,9} exception being Greece (5%).² Hence, inspite of an urban background, people in the city were quite reserved in their opinion on donation, perhaps an idea too personal to be shared with others. The sample here may be generalised to any urban Indian city, still there may be concerns due to the cultural diversity of the country, unlike other

Table 2 – Showing number of respondents' belief in God, marital status, registration by spouse, age of children, occupation, education and level of responsibility in their jobs.

Belief in God	Marital status		Spouse registered for body donation		Average age of respondents and their number		Average age of respondent's children		Number of children of respondents		
Yes	120	Married	111@	Yes	68#	<30 yrs	2	<10 yrs	3	No child	12
No	19	Widower	9	No	40	31–40	1	11–20	5	1	25
UD	2	Widow	8	Spouse no more	17	41–50	8	21–30	11	2	51
Total	141	Unmarried	8	Unmarried	8	51–60	13	31–40	45	3	13
		Divorced	3	NA	5	61–70	42	41–50	25	4	4
		NA	2	Divorced	3	71–80	45	51–60	10	>5	5
		Total	141	Total	141	81–90	21	61–70	0	NA	2
						>91 yrs	3	71–80 yrs	0	Total	112®
						UK	6				
Occupation of respondents (present or past)				Highest education achieved				Level of responsibility			
Homemaker	24	Industrial worker	4	Professional/post graduate	54	High	70				
Management	22	Govt servant	4	Graduate	49	Homemaker	26				
Armed forces	20	Insurance/banking	3	High school	19	Mid	23				
Engg/IT	19	Humanities	2	Primary/middle school	16	Low	14				
Teacher/education	11	Law	2	Not answered	2	Not specified	8				
Business	9	Railways	1	Not known	1	Total	141				
Not specified	7	Student	1	Total	141						
Clerical	6	Driver	1								
Medical	5	Total	141								

@: couples counted as one, #: couples counted as two, NA: not answered.

studies where samples were more homogenous. The respondents belonged to 17 geographical zones, but a significant number were from inner west and inner south (31.9%), perhaps indicated some unique reasons.

Social demographic factors

Gender and age distribution (Fig. 3, Table 2)

The distribution of age is more or less similar in the various studies. There were 96 (68%) men and 45 (31.9%) women with median age of 72 and 68 years, respectively, in this study. The respondents ranged from 22 to 91 years (both sexes), youngest female being 45 years. The number of respondents between 61 and 80 years for both sexes was 87 (61.7%) with a significant number of them aged above 80 years (17%), quite similar to data from New Zealand.⁹ In other studies, the percentages amongst the female donors were highest in Brazil at 67.4%,¹⁰ South Africa at 63.4% and with the minimum recorded in New Zealand at 50.8%, but it had more single women than men.¹ The average age for males and females were 60.6–69.8 years^{1,11} and 66.6 years,^{10,11} respectively, with a range from 19 to 102 years,^{4,9,11} highest recorded from the Netherlands. The Indian study signifies a male dominance in body donation and generally he takes his decision after 70 years.

Children, marital status and spouse registration (Table 2)

Most of the donors elsewhere were married with living children,^{1,4} a finding very similar to this study which had only 12 registrants without children (out of which 8 were unmarried). There were 78.7% (n = 111) married registrants, including 29 couples who had co-donated, with 6.4% (n = 9) widowers, 5.7%

(n = 8) widows and 2.12% (n = 3) divorcees. Other studies indicate married registrants ranging between 33 and 80%, unmarried females at 70.6%,¹⁰ widows making up 26% and widowers and divorcees at 13% each amongst both sexes.^{1,4,9} The number of unmarried females at 7% (except in Brazil¹⁰) and males at 6%⁹ was similar to the Indian study. Here the tendency to co-donate was at 52.2%, much higher than 38.2% amongst Hawaiians,¹² 37% amongst Dutch⁴ and 32.1% in the Americans.¹³ Co-donation in the Hawaiian study was observed more in female-gendered occupations such as preschool teachers, an interesting finding which however does not resonate in our study. Around half of Indian donors also declared their spouses to have registered for donation. As indicated earlier, the maximum number of respondents had two children (mean 2.1), with a mean age of 37.8 years, which compares well with other studies. In the multicentric study, it ranged from mean of 2.2 years and 42 years to 1.2 years and 31 years.¹ A higher married rate, stable relationship, higher prevalence of co-donation and spouse registrations are hallmarks of an Indian donor suggesting strong familial bonding and shared decisions.

Belief, faith, occupation, education and level of responsibility (Tables 1 and 2)

In India, 85% (n = 120) of respondents believe in God, similar to Brazil,¹⁰ but not in sync with other studies, where 18–79%^{1,4,11,14} showed no religious affiliation, highest recorded from Netherlands. The majority of donors were from Hindu community (92.17%) but make up 78.8% of the city's population,⁸ surprisingly there were no donors amongst the Buddhists who make the "other" dominant faiths. Most of the

Body Donation Information Easily Available?		Awareness Of Fate Of Body After Body Donation?		Where You Came To Know About Body Donation?		Have You Donated For Any Other Reason?			
no	94	yes	57	family, friends, word of mouth	66	yes	105		
yes	45	no	59	books, newspaper	63	no	23		
NA*	2	NA*	25	television, internet	14	NA*	13		
total	141	total	141	NGOs	5	total	141		
				any other source	5				
				self	5				
				NA*	6				
With Whom Discussed Body Donation		Family Members Registered for Body Donation		Specific Relations of the Respondent Who Registered For Body Donation				Advised Body Donation to:	
other family member, relative	43	no	79	father	16	son	5	friends	74
wife	43	yes	53	mother	9	daughter	5	other relatives	73
son	32	NA*	9	cousins and in laws	8	sister	1	NA*	37
self decision	31	total	141	husband	6			children	16
daughter	27			NA*	6			social organizations/ colleagues	10
husband	20			wife	5			advice to anyone	9
friends	7			brother	5			no one	2

Fig. 4 – Number of responses to general queries on body donation.

donors in the studies done elsewhere practice Christianity; however, donors with “strong” Christian religious beliefs were unwilling to donate in Greece.²

Higher education and higher levels of responsibilities in their jobs played an important role in body donation in India with 73% (n = 103) possessing graduate and postgraduate degrees, belonging to management, armed forces, information technology and engineering streams. Out of 24 homemakers, 15 had university degrees in political science, economics, engineering, arts and commerce; however, only three doctors (1 Gynaecologist and 2 Ayurveda) registered for body donation. Similar association of higher education and good income amongst body donors was observed in Greece,² Brazil,¹⁰ Serbia¹¹ and United States.^{2,7,11,13} Clerical and trade occupations were the commonest in the multicentric study,¹ while healthcare professionals formed 25% of 764 respondents in the Netherlands. Participation from doctors were almost nil from the Netherlands, United States and New Zealand.^{4,9,11,14} In a study done on medical students, the

willingness to donate body ranged from 13.5 to 31.9%, but they recommended the idea to others in 82.5% of cases.¹⁵ There is no study of medical students in India.

When a geographical assessment of donor distribution was done, there was higher clustering from Kothrud area (n = 29, 20.5%). Since, the literacy rates in Kothrud (81.70%—with 75.8% being graduates and postgraduates) and whole Pune city (79.89%)⁸ were comparable, a telephonic survey was done in this area. It revealed a disturbing trend which indicated body donation being a collective decision amongst friends and families in this close knit community to spare their children settled abroad from attending their last rites.

So, this study has revealed balanced and liberal ideas which generally emanate from higher education and belief in divine faith are prerequisites for body donation, contrary to other studies where no direct association could be established; perhaps their idea had percolated down to their social rubrics delinked from demographic factors. The reluctance from the medical fraternity is similar across all studies,

Table 3 – Number of responses to specific queries on body donation.

Main reasons for respondent's body donation	Reasons for not donating body prevalent in society	Misconceptions	Incentives for body donors	Why body donation chosen over organ donation
Aiding medical science and research	Religious issues	87	Medical care	NA
Gratitude	Superstition	76	No incentive	56
Dislike for cremation/burial/last rites	Family objections	61	NA*	36
Others	Inaccessibility of forms/information	48	Any other incentive	28
No relatives for last rites	Gender issues	16	Both medical and monetary	12
Cost of cremation/burial	Disrespect to cadavers	16	Monetary	7
	Restrictions on body donors for various diseases	11	Total	2
	Any other reason	11		141
	Marital status	6		
	Ignorance	2		
	Not answered	nil		
		34*		
		1		
		–		
		68		

NA: not answered, *: see Table 4 for some examples).

perhaps a sense of morbidity and mutilation perceived within close quarters influencing their decision.

Profile and attitudes of respondents

General queries on body donation (Fig. 4, Table 4)

The majority of respondents (n = 94, 66.7%) felt that body donation information is not available easily, but sourced by word of mouth from friends, relatives, books and local newspapers in 78.6% of cases. Unlike India, television and Internet played an important source of information in New Zealand (26%) and Ireland (22%), respectively.¹ Hospital and doctors provided information in United States and the Netherlands.^{4,11} “Personal contemplation” and sense of “personal achievement” than true altruism were important reasons for donation in the Netherlands.

As noted earlier, family plays an important role in body donation. Family members of 37.5% (n = 53) of respondents had registered for body donation. These figures compare favourably to the multicentric study (33%)⁴ and the one in New Zealand (40%).⁹ People discussed about their intentions with close family members 88–92%^{1,11} of the times, most often with their spouses or children, and fathers played an important role model. It suggests friends and doctors are not the preferred choice for discussing a personal decision. It has also been noticed across countries that the donors are magnanimous people with 80–89% of them donating for charitable reasons,¹ with slightly lower rate in India at 74.5% (n = 105). Participants from New Zealand (68%), Ireland (35%) and the Netherlands also registered for organ donation,^{1,14} an idea still in its infancy in India.

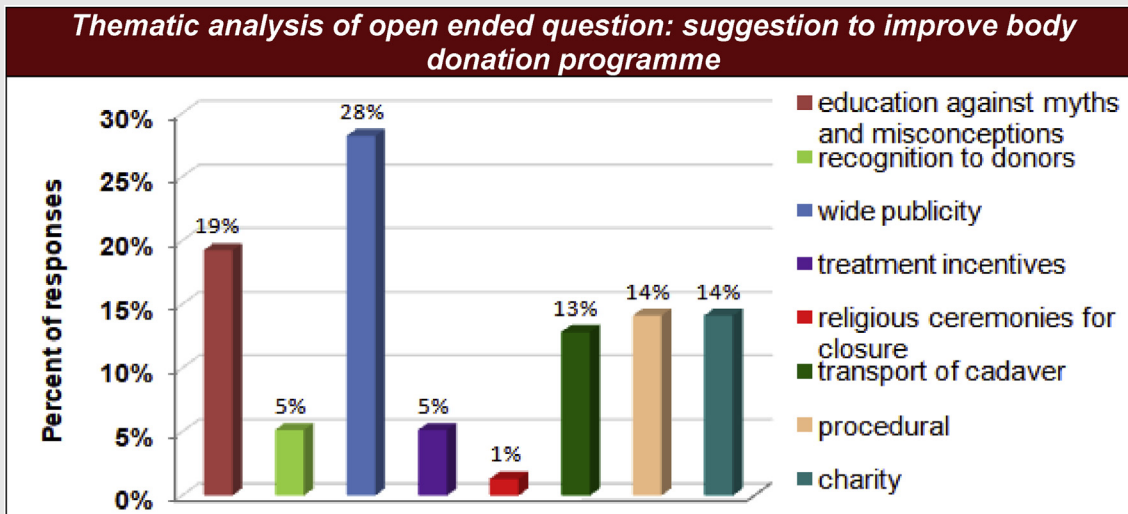
The donors in India, being more family oriented, trust close family members for a decision, are as magnanimous as their counterparts in other countries and advise their friends and relatives in equal measure but not to their children.

Specific queries on body donation (Table 3 & 4)

Various studies have revealed desire to aid medical science (78–82%), gratitude (20%), dislike for ritual of funeral (8–18%) and reluctance to spend on funeral expense (6%)^{1,9,11} as the most common reasons to donate, findings very similar to this study. A desire to be “useful after death” and donation for “future generations” are some of the reasons close to the Dutch.^{1,4} Religious issues, superstitions, family objections and gender issues are deterrents in the Indian context to donate, unlike other parts of the world. Incentives for donation is a sticky issue, considered inappropriate in West, while 39.7% (n = 56) donors here aspire for medical care with incentives. In Germany, donor families were entitled to “death benefit” allowance, but it has been abolished.¹⁶

This study is not without limitations. The sample size was calculated based on the premise that prevalence of body donation was 50% in the population, and no response correction was made. Owing to logistical constraints, a pragmatic sample was investigated. Many of the registered donors did not reply to the questionnaire, and many did not attempt all the questions; however, there were plenty of responses on how to improve body donation through publicity and education. This study attempts to offer new insights to understand our potential donors and endeavours to introduce concept of

Table 4 – Interesting comments and opinions to open-ended questions.



SUGGESTIONS TO IMPROVE BODY DONATION: SNIPPETS

1. Since in certain religions (Zoroastrian) like mine, where priests refuse to pray for the soul of an organ donor or body donor, some form of prayer for the repose of the soul should be initiated by the institution.
2. A nationwide dedicated phone number like 100 (Toll free) used by police should be there for body donation.
3. Every major hospital and medical college should have a separate cell for its promotion. Provision of on line registration to Institutional Body donation program.
4. Body collection to be done by the institution despite distance and on holidays.
5. Should be linked to Aadhar, driving license, voter card.

Other opinions in their own words which may improve body donation..

What is the most important misconception/myths/reasons NOT TO DONATE

1. Most people like prayers to be said for the peace of soul. If this cannot be done for a donated body, they would rather not donate.
2. As per Hindu religion, concepts of Heivan (demons), moksha etc are misconception regarding trouble to next of kin and other family members.
3. Hindus feel that without Pindadan, the deceased and his ancestors do not reach salvation. Fear of being criticized by relations to have abdicated duty by family members/survivors.
4. Rebirth not possible after body donation. Inhibition to donate being a lady
5. Fear: if we talk of body donation, we will die soon.
6. Among Parsis (Zoroastrians), the 4 day prayers on death may not be performed unless body is placed in the Tower of silence.

Do you feel that there should be INCENTIVES for body donors?

1. Medical care during lifetime (in Govt hospitals) and to survivors.
2. A Plaque bearing names of body donors in department.
3. Give star or ribbon as recognition which they can wear on daily basis.
4. There should not be any incentive otherwise it is not donation.
5. Many senior citizens from middle income and also from economically weaker sections of society will agree if they are given medical and boarding/lodging facility through old age home of army.

Why have you chosen body donation over organ donation?

1. Never thought about it. Don't know if one can donate organs after death.
2. If anything has to be given. Why only in parts? Give it full!
3. As I have grown old my family members are not ready to allow me for organ donation.
4. Have pledged both: organ donation incase brain dead, body donation after death.
5. I want to donate my organs. In her letter, she writes to "preserve her body as there is a provision like that. This way my relatives can come and visit the Department and see my body (Retired teacher).
6. One and the same thing.
7. Body includes all organs (hence no difference).
8. Concept of heart dead and brain dead not clear to me. I would prefer organ donation.

body donation in the community. It is contemplated that anatomy museums, brochures, information kiosks in hospitals and TV programmes (as tried in New Zealand) will spread the knowledge on body donation and answer the myths surrounding it. It is also contemplated to introduce clearing and thanks giving ceremonies^{1,9} for the friends and families of the donors to make donation more acceptable and provide an opportunity for closure to the departed.

In conclusion, socioeconomic and cultural differences had defined an American donor of 1990s as a religious, white, married, female homemaker of about 70 years, a high school graduate who chose not to have her remains returned to her family,¹³ while a contemporary Indian donor may be identified as “an individual Hindu male in his 70s, married with two children, religious, with a university degree, retired from an executive job with good family ties and charitable with a strong desire to aid medical science”. Body donation is a noble and selfless act, and Khalil Gibran in “The Prophet” had beautifully said:

“You give but little, when you give of your possessions. It is when you give of yourself that you truly give.”

Conflicts of interest

The author has none to declare.

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