

Evaluating awareness and perceptions of organ donation among paramedical and nursing students in an eastern Indian tertiary care hospital: focus on transplant coordinator's role: A cross-sectional study

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Received:23rd January2023; Accepted:29th November2023; Published:01st January2024

Abstract: *Introduction:* End stage diseases warrant organ transplantation as the ultimate life saving treatment modality. The purpose of this study was to evaluate and assess the level of knowledge, attitude and perception pertaining to various technical, legal and social aspects of the topic of organ donation, including the role of 'Transplant coordinator', among college students of nursing and allied paramedical courses in a tertiary care hospital in West Bengal. *Materials and methods:* The study was carried out in nursing and paramedical students of a tertiary care hospital in West Bengal. It was based on a questionnaire which sought information on the background knowledge about organ donation, knowledge about legislative provisions and organizational set up governing the procedures of organ donation in India and individual and impersonal attitudes and perceptions about the subject. *Results:* The study results show that most of the participants had a preliminary acquaintance with the concept of organ donation. The source of information for our participants were largely from social media (36%), television (23%). Lacunae were noted regarding the concept of living organ donation regarding the knowledge regarding 'Brain death' and the procedure of its evaluation, 33% of our respondents answered correctly. Mere 19.6 % of our subjects were aware of the existence of a legislation regarding organ donation in our country. Role of family members' consent was found to be more important than individual consent for pledging organ donation. 41 % subjects had some incomplete knowledge about the role of transplant coordinators in organ donation. The study brings out the inadequate knowledge persisting even among the nursing and paramedical students about the complete role of a transplant coordinator. *Conclusion:* Knowledge about technical and legal aspects of organ donation is inadequate among the subjects. Social media can act as a powerful tool for awareness generation among the masses. There is grossly inadequate knowledge about the proper role of transplant coordinator. Given the opportunity of proper training, the nursing and paramedical students can be encouraged to take up the role of a transplant coordinator of the institute and serve their role in the whole process efficiently.

Keywords: Transplant Coordinator, Organ Donation, Awareness, Knowledge.

Introduction

In every country, including India, there is a growing need of organ transplants. End stage diseases warrant organ transplantation as the ultimate life saving treatment modality. However, the number of organs salvaged from donors is meager when compared to the ever increasing demand. Around 1.8 lakh persons suffer from

renal failure every year, however the number of renal transplants done is around 6000 only [1]. National registry data shows, in the year 2020, 1780 liver transplants were carried out in India [2], whereas about 25-30 thousand liver transplants are needed annually in India as per the Directorate General of Health Services, Ministry of Health & Family Welfare, Government of India. National

Organ Transplant Programme statistics. Nearly every person who dies naturally, or in an accident, is a potential donor. As per the reports of the NCRB, an estimated 1.3 lakh people died in road traffic accidents in India in the year 2020 [3]. However most natural or accidental deaths do not culminate into salvageable organ donation. This can be attributed mostly to lack of timely consent from the relatives of the deceased. Human organ donation was legalized in India since 1994 through 'The transplantation of Human Organs Act', 1994 [4]. Even after so many years, myths, misconceptions and lack of awareness surround the topic of organ donation to a large extent, making it a challenging hurdle to overcome.

The purpose of this study was to evaluate and assess the level of knowledge, attitude and perception pertaining to various technical, legal and social aspects of the topic of organ donation among college students of nursing and allied paramedical courses in a tertiary care hospital in West Bengal. Though similar studies [5-7] have been done in other parts of India, such detailed questionnaire based study has hardly been done in this part of the country, to the best of our knowledge.

Material and Methods

The study was carried out in 123, 1st year nursing and paramedical students of a tertiary care hospital in West Bengal. A questionnaire was prepared based on the pre validated questionnaire prepared for this purpose by Singh R et al [8]. It was a semi structured, self administered questionnaire which sought information on the background knowledge about organ donation, knowledge about legislative provisions and organizational set up governing the procedures of organ donation in India and individual and impersonal attitudes and perceptions about the subject. The questionnaire was filled by the students in half an hour time. The medium of instruction and language of questionnaire was English as it is the medium of instruction in the institute, with clarifications provided in vernacular by the researchers when their help was sought for.

Institutional Ethics committee approval was received prior to starting the study vide institutional memo no.IPGME&R/IEC/2018/271 dated 25/04/2018.It was a cross-sectional

descriptive type of study. The duration of study was 10 months (February 2020-December 2020) which included one session with the students for getting their feedback on the questionnaire. Rest of the period was spent on background data analysis and writing of the paper. The completion of the project was halted several times in between due to the ongoing COVID crisis.

The study was carried out using convenient sampling. Inclusion criteria included all the 1st year nursing and paramedical students admitted in the session 2020-21 in the said medical college. The students having some issues in attending the questionnaire session or informed of some upcoming prescheduled leave for some purpose were excluded from the study. All the eligible students were contacted, and 123 students participated in the study and completed the questionnaire. Participation was voluntary and written informed consent was obtained from each participant. The ethics committee approval was sought from the institute ethics committee and was approved. The data thus collected were evaluated using the excel spreadsheets of Microsoft to come to conclusions. As it was a descriptive study, analysis based on percentage calculations and central tendency of the data were studied.

Results

Table-1 shows that most of the students are coming from a rural background. 73.7 % belong to nuclear family type and most of the belong to the low income family groups. Based on religion, our participants had a fair share of responders from several faiths. The study was conducted on 123, Paramedical students attached to a government medical college and Bsc Nursing students of a government nursing college affiliated with the Nursing council of India. The demographic profile of the study population has been listed in the following table, Table 1 (All values as percentages).

Table 2 shows the background knowledge about the topic of 'organ donation' in general. The notable observations from the survey results can be summarized as follows. Most of the participants are aware of the term 'organ

donation’ but most of them are of the opinion that it means ‘Transfer of organs from a dead body to a patient’. Most of the participants had come to know about organ donation from social media.

Table-1: Showing the demographic profile of study population. Values are expressed as percentages (%)										
Residence Type		Family Type		Family Income Range			Religion			
Urban	Rural	Nuclear	Joint	<50K	50K-100K	>100K	H	M	C	O
46.15	53.85	73.7	26.3	63.25	26.80	9.05	73.07	15.5	4	7.4
H = Hinduism, M = Muslim, C = Christianity, O = Other Religions										

Table-2: Results of part two of the questionnaire(Candidates had the liberty to mark more than one response)		
Domain examined: Background knowledge of organ donation	Options with coding used in brackets in respective manner	Codes with frequencies(%) in bracketsn=123
2.1.Have you heard about organ donation	Yes; No (1,0)	1. (95) 0(05)
2.2. From where did you learn about ‘Organ Donation?’	1.Newspaper 2.Social Media 3.Television 4.Family, friends and acquaintances	1. 25 2. 36 3. 23 4. 16
2.3. What does organ/tissue/ Blood donation mean to you?	1.Transfer of organs from a dead body to a patient; 2. transfer of tissues or organ from a dead body to a patient in need; 3. transfer of tissues/blood/organs from a living to a patient in need; 4.all the above (coded: 1, 2, 3, 4).	1. (70.5) 2. (15.6) 3. (8.7) 4. (5.2)
2.4. Which organs/ can be donated?	1.Kidney;2.heart ;3.lungs;4.liver;5.pancreas;6.intestine;7.skin; ;8.Cornea; 9.bones;10.veins;11.ligaments;12.tendons; 13.heart valves;14.cartilage .	1. (61.2) 8. (56.7) 2. (43.75) 9. (8.9) 3. (8.8) 10. (1.1) 4. (15.5) 11. (2.2) 5. (4) 12. (1.1) 6. (4) 13. (16.7) 7. (5.4) 14. (0)
2.5. Who can pledge for organ or tissue donation? Is there any age limit	1.Adult (>18 years);2.Minor (<18 years);3.Parents of Minors, after their death; 4.All of them (coded 1,2,3,4)	1. (53) 2. (4.8) 3. (8.4) 4. (12)
2. 6. Clinical findings necessary to confirm ‘death’ and irreversible cessation of all functions of the entire brain including the brain stem are:	1.Coma with a known cause;2. Absence of brain stem reflexes; 3.Apnoea (absence of spontaneous breathing) ;4.Above three tests should be carried out twice at an interval of 6-12 hrs by a team of medical experts. (Coded 1,2,3,4)	1. (9.9) 2. (16) 3. (0) 4. (33.3)
2.7. When are the pledged organs taken	1.In living condition if needed (for some special organs;2.after brainstem death ;3.any time after death. (Coded 1,2,3,)	1. (41.6) 2. (34.5) 3. (8.8)
2.8. Living donation is possible for:	1.Kidney; 2.portion of lungs;3. portion of liver ;4.portion of pancreas;5. portion of intestine. (Coded 1,2,3,4,5)	1. (50.4) 2. (11.7) 3. (18.9) 4. (3.6) 5. (4.5)

Percolation of information through interpersonal communication was minimal. Among these participants, most have heard about Kidney, cornea, heart and heart valve donation but only a handful of them (less than 10 %) know that vein, ligament and tendon can also be transplanted from a donor. None of the participants had the knowledge that cartilage can be donated. Regarding the confirmation of ‘death’ as irreversible cessation of all functions of the entire brain including the brain stem, only about one - third of the participants had the knowledge of the correct methodology of evaluation. Half of the participants had heard that, living donation is possible only for kidney and less than one-fifth knew that the same applies for a portion of liver as well.

Regarding the knowledge of the participants about the basic legislative and organizational set up of the procedure of organ donation in our country (Table 3), it was noted that ,a mere 3.6 percent were aware of the correct procedure that

a panel of doctors were eligible for declaring brain stem death. Most of them thought, it was the treating doctor who certified the brain stem death required for proceeding with the process of organ donation. It was however noted that, 34 percent had some knowledge about the role of a transplant coordinator of the institute with regard to his/her role in counselling the relatives regarding organ donation. However, regarding the complete role of a transplant coordinator, 41 % had the impression that his/her role is limited to counselling the relatives and doing related paper works. About one-fifth of the participants had the correct knowledge regarding the centralized organizational set up comprising of NOTTO-ROTTO-SOTTO, which is the controlling authority in all matters pertaining to organ retrieval and donation in our country. Regarding the cost of maintenance of the potential donor in the ICU, 37.6 % correctly opined that the procedural cost will be borne by the institution.

Table-3: Results of part three of the questionnaire (Candidates had the liberty to mark more than one response)

Domain examined: Knowledge about Legislative and organizational set up	Options with coding used in brackets in respective manner	Codes with frequencies (%) in brackets n=123
3.1. Who will certify brain stem death?	1. Doctor in charge of the hospital (Medical Superintendent); 2. Doctor nominated panel of doctors appointed by the appropriate authority; 3. Neurologist/ neurosurgeon/ intensivist nominated from a panel appointed by the appropriate authority; 4. Doctors treating the patient; 5. A medical board consisting of a panel of four doctors carries out the tests together to certify brain death. (Coded 1,2,3,4,5.)	1. (19.3) 2. (12) 3. (19.3) 4. (26.5) 5. (3.6) 6. (19.3)-Did not answer
3.2. Who is the first person to counsel the relatives of the brainstem dead patient for organ transplant?	1. Doctor in charge of the hospital (Medical Superintendent); 2. Doctor declaring death of the patient; 3. Doctor nominated by panel of doctors appointed by the appropriate authority; 4. Transplant coordinator of the institute (Coded 1,2,3,4.)	1. (8.0) 2. (18.4) 3. (16.1) 4. (34.5) 5. (23)-Did not answer
3.3. Role of a ‘ Transplant Coordinator’ in organ and tissue transplant are	a) Counsel the grieved family, make them compatible and approach the subject of eye donation and later on solid organ donation; b) Inform the nodal officer and coordinate with the ICU staffs to maintain the patient on ventilator and organise organ retrieval;	1. (13.3) 2. (8.4) 3. (1.2) 4. (41) 5. (36.1)-Did not answer

Domain examined: Knowledge about Legislative and organizational set up	Options with coding used in brackets in respective manner	Codes with frequencies (%) in brackets n=123
	c)He/she has to ensure that all the paper work is correctly done and that the family receives the body as soon as possible; (Coded 1 for a &b, 2 for b& c, 3 for a,b & c and 4 for a & c)	
3.4. In one's living condition he/she can donate some special organs to:	1. Near relative; 2. Any Unknown person; 3. Both are correct	1. (52) 2. (23) 3. (15) 4. (10)-Did not answer
3.5. Nodal agencies for organ transplantation in India is/are:	1. NOTTO-ROTTTO-SOTTO: 2. there is no such nodal agency: 3. Department of social justice , Government of India; 4. under the control of individual state government with no central control. (Coded 1,2,3,4)	1. (19.6) 2. (5.3) 3. (24.1) 4. (8.7) 5. (42.3)-Did not answer
3.6. Who will bear the cost for maintenance of the cadaver in the ICU till the time of donation .	1. Donor: 2. Treating Institution; 3. Recipient's family; 4. All of them in part.(Coded 1,2,3,4)	1. (10.8) 2. (37.9) 3. (13.5) 4. (37.8)
3.7. Who can give consent for organ or tissue donation after death of an individual ?	1. Near Relative; preferably spouse or children. 2. A very close friend; 3. Institute where the person died; 4. All of them(Coded 1,2,3)	1. (40) 2. (8) 3. (34) 4. (6) 5. (12)-Did not answer

Table-4: Results of part FOUR of the questionnaire (Candidates had the liberty to mark more than one response)

Domain examined: Attitude and perceptions	Options with coding used in brackets in respective manner	Codes with frequencies (%) in brackets n=123
4.1. Would you like to pledge for organ or tissue donation?	1. Yes 2. no 3. Haven't decided (Coded 1,2,3)	1. (47.1) 2. (15.1) 3. (37.8)
4.2. Would you like to discuss with family members about organ donation.	1. Yes 2. No 3. Haven't decided yet. (Coded 1,2,3)	1. (50) 2. (20.5) 3. (29.5)
4.3. According to you, probable reasons of not pledging for organs	1. Religious belief 2. Delay and difficulties for funeral 3. Concern about chances of misuse of organs 4. Lack of concerned knowledge about whom to approach 5. Lack of proper infrastructural facilities 6. Others, specify (Coded 1,2,3,4,5,6)	1. (20.9) 2. (10.3) 3. (19.6) 4. (35.5) 5. (23.8) Others:1. Concern regarding Organ Donation might leave the body disfigured before funeral. 2.Lack of social awareness 3.Concern over adequate end of life care at health facility if pledging has been done beforehand.
4.4. Would you like to become a 'Transplant Coordinator' in future?	1. Yes 2. no 3. Not sure(Coded 1,2,3)	1. (51.3) 2. (10.3) 3. (38.4)

The evaluation of attitude and perception of the participants (table 4) revealed, that, a significant majority (37.8%) were unsure about opting for organ /tissue donation pledging. However half of them opined that, they would like to discuss about the same with their family members. In response to the open ended question about their perception for not pledging of organs, the most common answers received were lack of proper knowledge and social awareness, concern regarding the possibility that organ donation might leave the body disfigured before funeral and concern over adequate end of life care at health facility if pledging has been done before hand. Last but not the least at least 50 % of the participants expressed their interest to become a transplant coordinator of their institute in future.

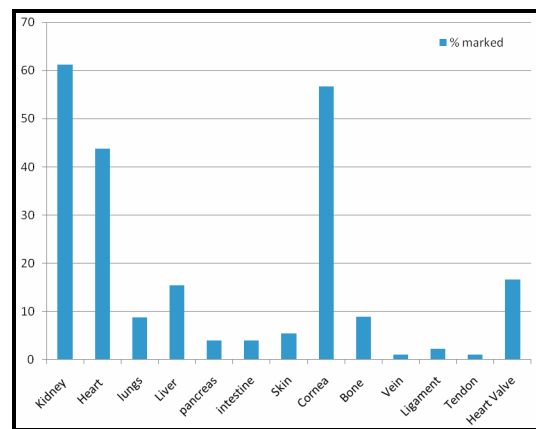
Discussion

The study results show that most of the participants had a preliminary acquaintance with the concept of organ donation. In a previous study conducted by the authors [9] among first year medical students, it was noted that the students, be it medical, nursing or paramedical are nowadays aware about the concept of organ donation in general, which is a very positive sign. Nursing and paramedical students play a very vital role in educating the masses [10] in general and acquaintances in particular about the concept of organ donation. Another point of note in this study is that, a fair mix of rural-urban population was present, which helped us to get the larger picture of the status quotient relevant to the attitudes and perceptions of the subjects.

The sources of information for our participants were largely from social media, television and news papers. In similar studies across the country and worldwide [11-14], television and social media form a strong source of information regarding the subject. In our study, in mere 5% , the source of information was from friends ,family and acquaintances, which is in contrast to the findings in the studies by Ramadurg [15] and Vincent et al in south India, where it was 13 % and close to 30 % respectively. These points aptly highlight the fact that, television media and social media channels can play a vital role in spread of awareness which will have a cascading effect on society and gradually family and friends will also become strong sources of spread of awareness.

Most of the studies have tested the participants, background knowledge regarding the organ donation in general, which yielded similar results as our study. However, we noted, that, ‘organ donation’, to donation of most of the participants meant donation limited to kidney, cornea and heart donation, Fig.1. A similar lacunae in information was present even among postgraduate students as exemplified in a similar study [16] among post medical graduates.

Fig-1: Awareness among study subjects regarding organs that can be donated, n=123. Multiple responses were recorded



Regarding the knowledge regarding Brain death and the procedure of its evaluation, 33% of our respondents correctly answered. Vincent, in their study noted that, though 46.9% of the study participants knew about the correct definition of brainstem death, 17.7% of the study participants had moderate knowledge regarding the brain death definition. This difference might be due to wider exposure of our subjects to the topic of brain stem death, as this institute serves as a nodal centre of organ donation in this part of the country.

In another study done in Puerto Rico[17], 80% of the study participants knew the correct definition for brain death, but, their responses were collected based on choices (yes/no options) and not open-ended question as in our study. The correct concept about the definition of brain stem death is a very crucial aspect of the awareness campaign, as the first step towards organ donation is possible only after declaration of brain stem death. Myths

and prejudices surrounding the term 'Brain Death' needs to be alleviated at the very outset in any awareness programme. Another lacuna noted was, regarding the concept of living organ donation. Half of the participants had heard that, living donation is possible only for kidney and less than one-fifth knew that the same applies for a portion of liver as well. This aspect of the knowledge domain has not been tested in other recent studies.

Although quite a large number of our subjects were aware about the concept of brain death, merely 3.6 % were aware about the procedural details that are followed for declaration of the same. We had also tested their knowledge regarding the role of the Transplant coordinator in the institute. 41 % had the impression that his/her role is limited to counselling the relatives and doing related paper works and were mostly unaware of his /her role to Inform the nodal officer and coordinate with the ICU staffs to maintain the patient on ventilator and organise organ retrieval. This again is a very important outcome from our study, as the role of a transplant coordinator is of paramount importance in the entire process of organ donation and so their role cannot be overemphasized.

The Government of India has enacted a law (Transplantation of Human Organs [Amendment] Act 2011) to protocolise and promote organ donation following brain death [18]. There is a National Organ and Tissue Transplant Organization (NOTTO) under the Directorate General of Health Services, Ministry of Health & Family Welfare, Government of India, at national level, Regional Organ and Tissue Transplant Organizations (ROTO) and State Organ and Tissue Transplant Organizations (SOTTO) at regional and state levels respectively for this purpose.

About 19.6 % of our subjects were aware of the existence of a legislation regarding organ donation in our country. This figure is somewhat close (29%) to that observed by Vincent et al, among undergraduate medical and nursing students in Puducherry, India. However, the percentage for the same was only 13.9%, when the subjects were students from General Arts and Science College in Tamil Nadu, India [19]. It is interesting to note, that, in a study conducted by

Dasgupta et al [20] among urban slum dwellers in West Bengal, 72.7% people knew that there are certain laws regarding organ donation. This high percentage may be owing to the fact, that, it was a Yes/No question and the high percentage could be due to chance factor. The overall data suggests, that, awareness of the general population, including those who are close to the medical field, about the legal and organizational set up of organ donation India is quite inadequate. This lacunae needs to be filled up in order to stimulate the organ donation movement in a proper fashion.

In our study, we noted, that 40 % subjects thought that, after death, the consent for organ donation can be given by near relative; preferably spouse or children, which points out, that, 60 % of the remaining subjects did not have clear idea regarding the legislation, which states, that, a person legally in possession of the deceased person can sign the consent form, which is usually done by a parent, spouse, son/ daughter or brother/sister.

As to the question regarding who will bear the cost for maintenance of the cadaver in the ICU till the time of donation, quite interestingly, we found two close answers. 37.9% marked it as the treating institution and 37.8 % marked that the cost will be borne by partly by the Donor, Recipient and treating institution. Legislation states that, potential donor needs to be medically maintained in ICU till the time of donation. From the time family agrees to donate organs and tissue, all charges are borne by the treating hospital and donor family is not charged any further. This concept needs to be highlighted as confusions regarding it may dampen the spirit of the organ donation movement. This is a very unique outcome noted from our study.

A significant majority (37.8%) were unsure about opting for organ /tissue donation pledging, but half of them opined that, they would like to discuss about the same with their family members. This clearly shows the importance of 'family' in the decision making process in our culture. Family members play a vital role in India toward any decision-making [21] and they also need to be taken into

confidence. This fact should be borne in mind while designing awareness programme road maps in future. Vincent et al also noted that, 65.3% of the subjects agreed that permission from the nearer family member was also very essential.

In terms of the myths, misconceptions and apprehensions surrounding the decision for organ donation, the most important was, lack of concerned knowledge about whom to approach in the period of crisis. This emphasises, the role of the Transplant coordinator of the institute. Our study brings out the inadequate knowledge persisting even among the nursing and paramedical students about the complete role of a transplant coordinator. However, the study also shows that, half of them are willing to come forward to take up the role of a transplant coordinator as it is a professionally challenging, yet satisfying job opportunity.

Limitation: To us, the main limitation of this study is the sample size. Future studies attempting to include more medical colleges can be taken up to increase the statistical reliability of the data.

Conclusion

As opposed to the other awareness assessment studies on this topic, the key differences in our study were quite a few. Firstly, the questionnaire had several open ended questions attempting to test the affective domain of the subjects about the topic. Secondly almost none of the questions had Yes/No, type of options and had multiple correct options. So, the level of awareness could be assessed more objectively.

Thirdly, we tried to present before them how the role of a Transplant coordinator can emerge as a new opportunity for them to participate in the system for which they need to be trained. In the whole process, the key take home messages from our study are, that, social media can act as a powerful tool for awareness generation among the masses, level of awareness is still lacking, specially with respect to the legal and organizational set up guiding the system of organ donation in our country and last but not the least given the opportunity of proper training, the nursing and paramedical students can be encouraged to take up the role of a transplant coordinator of the institute and serve their role in the whole process efficiently.

Financial Support and sponsorship: Nil

Conflicts of interest: There are no conflicts of interest.

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Cite this article as: Sinha I, Bhattacharya A, Bhattacharya S and Bhattacharya A. Evaluating awareness and perceptions of organ donation among paramedical and nursing students in an eastern Indian tertiary care hospital: focus on transplant coordinator's role: A cross-sectional study. *Al Ameen J Med Sci* 2024; 17(1):18-26.

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