

Effect Of Awareness By The 99th Edition Of Mann Ki Baat On Organ Donation And Transplantation By Prime Minister, Shri Narendra Modi: A Knowledge, Attitude And Practice Gap Study In Ujjain.

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Abstract

Background

On the 26 March 2023, the Honourable Prime Minister of India, Shri Narendra Modi addressed the Nation on Organ Donation and Transplantation in his 99th episode of Mann Ki Baat. There was also previous studies conducted on the effect of Mann Ki Baat on Organ Donation and Transplantation, and awareness about organ donation in different subgroups and populations in India.

Method

The present study was conducted in Ujjain as cross-sectional study among five subgroups viz. dialysis and organ failure patients, transplanted patients, general population including relatives of patients, medical staff and medical doctors; to evaluate the knowledge and attitude towards organ donation and transplants and effect of the 99th edition of Mann Ki Baat on Organ Donation and transplantation by Prime Minister (PM) Modi. The attached survey Questions were circulated in Google Sheets in three languages during August-October 2023.

A total of 1098, 700, and 70 responses were registered in English, Hindi, and Marathi language. The median age of survey participants was 35 years and nearly 60 per cent was male. Around 33 per cent of respondents had a rural background and most of the survey participants were graduates as per their educational level. Nearly 85 per cent of the participants said that the Mann Ki Baat episode increased not only their existing awareness but also their willingness to become organ donors themselves.

Results

Nearly three-quarters of the survey participants believed that they were ready and willing to discuss the possibility of organ donation among their families. On the question- "Do you agree that the government is actively working on the promotion of organ donation?", the majority of the responses was 'yes' with the highest frequency in Hindi responses followed by English and Marathi; and by percentages; these are 87 percent, 77 percent and 61 percent respectively.

Conclusion

This survey helps us in landscaping the current knowledge and attitude of diverse group of people right from patients to primary care providers to the medical fraternity. Significant knowledge gap exists, especially in rural settings, and measures are required to overcome this barrier. The researchers also noticed that Mann ki baat proved to be an effective way to create awareness and boost the existing knowledge about organ donation.

Key words: Mann Ki Baat, Organ transplantation, Living donor, Deceased donor.

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I. Introduction

Organ transplantation is one of the most successful advances in modern medicine. Transplantation most often provides the only chance for survival for patients with end-stage disease.¹ Global Observatory on Donation and Transplantation² 2021 data reported 0.4 deceased donor transplants per million population (pmp) in India as compared to the global data of 6.37 pmp. More interestingly, no reporting of organ donation after cardiac death was done in India. This data also reported a total of 8.8 pmp organ transplants performed in India in comparison to 24.08 pmp globally. According to the International Registry in Organ Donation and Transplantation 2021 report,³ India reported 0.4 pmp deceased donation rate and the nation was ranked at the bottom of the list, where US and Spain topped with 41,60 and 40,80 pmp donation rates. This data depict that our organ donation lags significantly as compared to the global figures when it comes to deceased organ donation and transplantation. A

recent report⁴ estimated the need of 175000 kidney, 40000-50000 liver, 50000 heart, 50000 lungs and 2500 pancreas transplantations in India. A large gap exists between the patients who require organ transplants and the available organ donors. There is a need to promote deceased organ donation.⁵ This substantial supply and demand mismatch is concerning; and various measures are being implemented to overcome this gap. And hence, creating awareness among the general masses about organ donation remains a key concern. The Prime Minister of India, has taken the initiative for reaching to the masses through a radio broadcast titled Mann ki Baat; and the first edition was aired on 3 October 2014. These episodes cover various public-oriented subjects. The 102nd episode of the radio talk was aired on 18 June 2023. On 26 March 2023, The Prime Minister of India in his Mann ki Baat emphasized on creating awareness for organ donation in the 99th edition. The episode was filled with information on organ donation and transplantation in a comprehensive and easily understandable manner. There has been a few knowledge, attitude and practice gap (KAP) studies about organ donation in India.⁶⁻¹⁰ However, all had inherent limitations. Hence, the investigator of this paper provide a comprehensive Ujjain District report in the survey about KAP of organ donation.

II. Objective

The basic objective of this study is to assess the effect of the single edition i.e. the 99th episode of the Prime Minister's monthly radio talk Mann ki Baat on the National Broadcaster, the All India Radio on Organ Donation and Transplantation on 26 March 2023, to the Ujjain District People. The study also measures the effect of Mann ki Baat on the knowledge, awareness, and practices in organ donation among the medical masses. This study helps in understanding the problem statement which in turn, can help in expanding the deceased donation practices in India.

III. Methodology

Study design

This was a descriptive, cross-sectional survey, conducted through pre-validated structured questionnaire. The study was conducted in Ujjain district and in our institute over a period of three months between August 2023 to October 2023.

Study population

The study participants included medical doctors, medical staffs, general population, transplanted patients, dialysis and organ failure patients

Sampling/sample size

A non-probability sampling technique (convenience method) was employed to reach to the representative population in our institutes. Total of 2000 participants were included.

Study instrument

The questionnaire was designed which consisted of two sections. Section one was about respondent's personal information including gender, age and education. Section two of the questionnaire included questions related to participants knowledge, attitude and practices regarding Organ Donation.

Ethical considerations

Written informed consent was obtained from all the respondents before the start of the survey. Participation in this research was voluntary. Participant identity was kept confidential. The study was exempted from ethical committee clearance; as de-identified data were used in this survey. The researchers abided with the declaration of Helsinki, and the declaration of Istanbul. The anonymity of the participants was respected, and only anonymized data were used for analysis. The authors also clearly stated in the survey form that the response recorded would be completely anonymized, and so, formal consent form was not required for conducting this study.

Method

A cross-sectional survey of the impact of Mann ki Baat on organ donation was developed by one of the study investigators (SB) with input from the study steering committee (SB, PW, PS). There was no modification in the questionnaires for final distribution. The survey was plotted in three basic languages- Hindi, English and Marathi. The survey questionnaire was translated into Marathi by a professional translator with the Marathi version subsequently corrected by a Marathi-speaking Physician (PW). The survey comprised an introductory line about the Mann ki Baat episode along with the You-tube link of the episode. The survey questionnaire was first distributed among 25 medical staffs for measuring the validity and reliability, and the result of this pilot survey was also included in the final analysis. The survey was circulated in google form from 1 August 2023 to 7 October

2023. The data were locked on 1 October 2023 for analysis. Invitations to participate were distributed to all the members of ISOT which comprises nephrologists, general surgeons, urologists, intensivists, transplant coordinators, medical students, and staffs through e-mail (a sample of convenience with single stage sampling technique). During the data collection period, one reminder WhatsApp mail was sent out daily reminding invited individuals to please complete the survey if they had not yet done so. Snow ball sampling was also allowed. The set of questions used in the study questionnaire are given below; and the graphical presentation of the analysis is given in figures 1 - 20. Statistical analysis was performed in STATA 16. A p-value of below 0.05 was considered statistically significant. No formal sample size calculation was planned in the survey. The data were reported as numbers, percentages. No continuous data were analysed, and all the categorical data were reported. Chi-square was used for comparison groups of English, Hindi, and Marathi wherever justified for comparison.

Questionnaire

The 22-set questionnaire is given below:

1. Are you aware about organ donation and transplantation?
2. What is the cost of kidney transplant as per your knowledge?
3. Which is better and cost effective for kidney failure- dialysis or transplantation?
4. Have you heard of Prime Minister (PM) Modi Speaking on Organ Donation and Transplants recently in the 99th edition of Mann Ki Baat?
5. Did the recent episode of Mann Ki Baat by the Prime Minister increase your awareness and/or willingness to become an organ donor?
6. Did you discuss with your family members about their wishes regarding organ donation after death after watching Mann Ki Baat by the Prime Minister?
7. Have you shared the awareness video of Organ Donation and transplants by PM Modi in Mann Ki Baat?
8. After hearing PM Modi's Mann Ki Baat on organ donation, are you more willing to donate organs and sign donor pledge Form No 7?
9. Do you agree that the government is actively working on promotion of organ donation?
10. Do you know the concept of brain death in organ donation?
11. Do you know the concept of donation after cardiac death (DCD) in organ donation?
12. How many organs one can donate after being declared brain dead?
13. Are you aware that it is possible to donate organs after death to help save someone else's life?
14. How many organs one can donate after being declared brain dead?
15. What was the age of the youngest deceased donor in India as mentioned by PM Modi in Mann Ki Baat?
16. Do you agree that One Nation One policy and no requirement of domicile certificate for Organ Donation as envisioned by the PM Office will change the scenario of organ donation?
17. Do you think that in death certificate, additional column of mandatory reporting of brain death (Yes/No) should be included?
18. What should the family of organ donors expect from Government in return of organ donation?
19. What should be the way forward for promoting organ donation awareness drive?
20. Should women/girls and children be given priority in deceased donor organ allocation process?
21. Do you think organ allocation process is transparent?
22. Is organ- tissue donation and body donation possible simultaneously?

Additional set of question corresponding to the medical staff only included:

- 1) Has there been an increase in the number of query on organ donation after Mann Ki Baat by PM Modi on organ donation?
- 2) Would PM Modi's Mann ki Baat on organ donation be useful as IEC activity for donor conversion in counselling?
- 3) Who can declare brain stem death? Findings A total of 1093 responses in English, 689 in Hindi and 67 in Marathi language were registered.

IV. Results & Findings

Figures 1 to 20 depicts the response of the study participants in the survey. In response to the question, "Did you discuss with your family members about their wishes regarding organ donation after death after watching Mann Ki Baat with the Prime Minister?", 71 per cent of the respondents said 'Yes' and 28 per cent declared 'No' which were registered in English. Hindi responses had similar distribution with 82 per cent and 18 per cent as 'Yes' and 'No' respectively. In contrast, responses in Marathi were 50 per cent 'Yes' and 50 per cent 'No', which were statistically significant as compared to other languages (p-value < 0.001). To the question, "Have you shared the awareness video of Organ Donation and Transplants by PM Modi in Mann Ki Baat?", Hindi responses had the highest number 'Yes' of 80 per cent as compared to 64 percent and 36 percent in English and Marathi respectively; this difference was statistically significant (p-value < 0.001). For the question, "After hearing PM Modi's Mann Ki Baat on organ donation, are you more willing to donate organs and sign donor pledge Form No

7?”, 83 percent recorded ‘Yes’ and 17 percent ‘No’ for English responses, and ‘Not sure’ was not recorded. ‘Not sure’ response was 20 percent and 50 per cent in Hindi and Marathi, and 92 this difference was statistically significant (p -value < 0.001). To the question, “Do you agree that the government is actively working on promotion of organ donation?” Majority of the responses were ‘Yes’ with the highest percentage in Hindi (86 %) followed by English (77%) and Marathi (61%). On the question, “Do you know the concept of brain death in organ donation?”, majority had an affirmative of ‘Yes’ with 92 per cent, 82 per cent and 66 per cent for English, Hindi and Marathi respectively. ‘Yes’ response was noted for the question, “Do you know the concept of donation after cardiac death (DCD) in organ donation?” in 82%, 74% and 54% in English, Hindi and Marathi responses respectively. To the question, “How many organs one can donate after being declared brain dead?”, low percentages have been recorded as 8 or more in 56 percent, 26 percent and 35.8 per cent in English, Hindi and Marathi respectively (Figure 9). To the question, “What was the age of the youngest deceased donor in India as mentioned by PM Modi in Mann Ki Baat?”, ‘No idea’ was reported in 41.0 percent in English, 38.0 percent in Hindi and 70 percent in Marathi respectively (Figure 10). To the question, “Do you have a person in your family who has organ failure and needs/needed organ transplant?”, 74 percent recorded ‘Yes’ in English while 54.10 per cent and 35.80 per cent recorded in the affirmative in Hindi and Marathi respectively. Majority of the respondents in English group were medical staff (27.90%) and doctors (33.90%) while organ failure (46.30%) patients were more in the Marathi category. In all the languages, male participants outnumbered the females, with a ratio of 2:1. As per the results, significant percentage of responses showed that they were aware about organ donation and transplantation, and they knew that it’s possible to donate organs after death to help someone else’s life (Figure 4 and 6). To the question of knowing about 99th edition of Mann ki Baat, only 50.70 per cent of the Marathi respondents were aware of this radio talk. For the question, “What should the family of organ donors expect from the Government in return of organ donation?”, majority of them in all the three languages stated that near relatives of the deceased donor should get the high priority in case of need of organ transplant in future. To the question on what should be the way forward of promoting organ donation awareness drive, majority of them selected a holistic response of ‘all the above’ while 10 to 20 per cent of the respondents chose more episodes of Mann Ki Baat. Majority of them selected that women/girls should be prioritized for availing of donor transplantation of the deceased (Figure 15). One-fourth of the survey respondents are unsure about the transparency of current organ allocation practices (Figure 16). On the question, “Would PM Modi’s Mann Ki Baat on organ donation be useful as an IEC activity for donor conversion in counselling?”, most of the medical staff selected the ‘Yes’ option in English (71.2%) and Hindi (72.1%) language. 42 percent to 77.40 per cent people selected a positive response to the question, “Has there been an increase number of query on organ donation after Mann Ki Baat by PM Modi on organ donation? (Figure 18).

V. Discussion

On 26 March 2023, the Honorable Prime Minister of India Shri Narendra Modi addressed the nation in his 99th episode of 'Mann Ki Baat' in which he talked about the impact and power of organ donation that changes the course of lives for several people. According to the National Organ Tissue and Transplantation Organization (NOTTO) 2022 data, of the 15,556 organ transplants that happened in India in 2022; only 2,765 organs came from the deceased donors despite efforts being made over the years to increase cadaver organ donations. Though the numbers have gone up from 837 cadaver donations in 2013 to 2,765 in 2022; lack of awareness, and social and religious beliefs remain the biggest impediments to organ donation from brain-dead patients who do not have any hopes of a revival. NOTTO estimates that less than one in every five organs transplanted in India comes from a deceased donor. The researchers conducted this survey amongst nearly 2000 people. This heterogeneous group of people included the dialysis and pre and post-transplant patient population, the health care workers including the paramedical staff and doctors and the general population including relatives of the patients. The median age of the people who took part in this survey was 50.9 years and nearly 60 per cent of the respondents was male, 33 per cent of the respondents had a rural background and most of them were graduates by their educational level. Nearly 96 per cent of the survey participants were aware of the concept of organ donation and transplantation. Most of the participants believed that organ transplants are expensive with out-of-pocket expenditures going up to 5-10 lakh rupees. It came as no surprise that nearly 44 per cent of the respondents was unaware of the cost-effectiveness of transplantation over a prolonged dialysis therapy. While most of the people who took the survey understood that the deceased organ donation exists and benefits people’s lives¹¹. Ababat passed away 39 days after she was born. Mr. Modi praised the parents’ decision to donate her organs and save the lives of strangers in need. Similarly, the PM spoke to the son of the late Chowdhary, who was killed in a road accident, and lauded the family’s decision to donate her organs, which saved the lives of four people and gave two others the power of sight. What came as an absolute surprise was that after the episode of the “Mann ki Baat” by the Honourable Prime Minister, nearly 85 per cent of them said that the episode increased not only their existing knowledge and awareness but also their willingness to become organ donors themselves. Nearly three-fourth of the survey participants believed that they were ready and willing to discuss the possibility of organ donation among their families. Check Brand,

a Sentiment Analysis and Digital Ranking Firm conducted a study in the second quarter of 2020. Honorable Prime Minister of India Shri Narendra Modi was placed fourth overall in all relevant categories defined by Check Brand which features actors, politicians, brands, CEOs, CMs and cricketers. Given the PMs' staggering digital presence, it comes as no surprise that after the episode on organ donation, nearly 80 percent of the survey respondents were more willing to donate organs and sign the Donor Pledge Form 7. This begs the question that if one dedicated episode can have such a humungous impact on people's attitudes toward organ donation; what can constant social media engagement and digital campaigns by the PM centred around organ donation do? It was gratifying to see that nearly 75 per cent of the survey respondents believed the present government is actively promoting the concept of organ donation. Awareness levels about the types of deceased organ donation have also increased; 92 per cent of the survey participants were aware of the concept of donation after brain death determination; and surprisingly, 82 per cent was actually aware of the fact that the donation of organs is not only plausible but also possible after cardiac death (DCD or donation after cardiac death). Nearly half of the respondents were not aware that after the declaration of brain death, 8 or more organs of the deceased can be harvested into the body of a needy individual; this figure is really disappointing¹². According to the Global Observatory on Donation and Transplantation (GODT) data, India has an organ donation rate of about 0.52 per million population (pmp) in comparison to the organ donation rate in Spain which has the highest rate in the world with 49.6 per million population. To achieve a 94 self-sufficiency in the field of organ donation, India needs an organ donation rate of 62 pmp. Going forward, it only makes sense to promote not only DBD donations but also DCD donations to meet this huge demand-supply gap of organs. Awareness campaigns should not only focus on the 'why's and 'how's of organ donation but also 'when' i.e. when can a person donate their organs. And the answer is both after brain death declaration and in some centres across India even after cardiac death determination under controlled settings. Most of the survey participants believed that an incentive- financial or otherwise (health card for the family members, priority allocation of the deceased organ donor's family member on a waitlist, etc.) would boost the organ donation rates in the country. Keeping in mind that this survey was anonymous and included a geographically, socially and educationally heterogeneous group of people; the notion of incentivizing organ donation was stated by the majority. Although organ donation has traditionally been considered an act of nobility and altruism, non-financial incentives like honouring the donors' families and health cards for the family members may serve in the bigger interest of expanding the deceased organ donor pool. In turn, it may ultimately serve the nation well. Women and children are amongst the most marginalized and socially disadvantaged groups in India. They are financially and socially dependent on others in the family. Organ transplantation is no exception. More than 75 per cent of all the organ donors in India are women whereas only about 25 per cent of the organ recipients are women. Keeping this in mind, the survey participants were asked whether women and children should get priority allocation points on the waitlist. While most of the respondents gave a resounding 'Yes' to the question, nearly 44 per cent of participants were either against this concept or were not sure about its utility. Seeing as women are at a triple disadvantage- access, wait-listing and sensitization; the concept of priority allocation really ensures equality of opportunity. The onus lies with the state and central health authorities; and the transplant coordinators to find subtle and nuanced ways to introduce the concept of priority allocation and explain the logic behind it to the pretransplant waitlisted population on dialysis¹³. According to the estimates drawn up by the Directorate General of Health Services, around 1.8 lakh persons suffer from renal failure every year. In 2022, the total number of kidney transplants stood at 11,423 of which 9,834 were from living donors. DGHS estimates that in India, about 2 lakh patients die of liver failure or liver cancer annually. In 2022, the total number of liver transplants done in India was 3718 of which of which 2957 was from living donors. About 50000 people suffer from heart failure annually. In 2022, just 250 transplants have been done in the country. While these estimates are depressing, there is light at the end of the tunnel, it seems. Most of the survey participants want more information on organ donation, and believe that increased visibility on the social media platforms and media attention, more episodes by the PM on organ donation and engaging the young minds in schools and colleges can positively impact the organ donation rates. While the majority of the respondents were aware that a law exists to regulate organ and tissue donation in the country, nearly 40 per cent believed that the process of organ allocation was not transparent. One way to remove peoples' misconceptions and increase their trust in the organ allocation system is to make the policy for allocation uniform across the country- 'one nation one policy'. Increased utilization of transplant coordinators to 95 impart information to organ failure patients and educate their relatives about the process of waitlisting, allocation point systems and potential waiting time on the list, can help make a patient well-informed to make a decision, and trust the organ allocation system more¹⁴.

Honourable Shri Narendra Modi Ji (PM) cherished a desire for a long time to know the Mann Ki Baat of people who do such noble deeds and share it with the countrymen as well. In the 99 edition of Mann Ki Baat, PM Modi ji connects with a lovely daughter, a father of a beautiful angel and her mother. The father's name is Sukhbir Singh Sandhu ji and the mother's name is Supreet Kaur ji...this family resides in Amritsar, Punjab. After many a prayer, they were blessed with a very beautiful girl child...a doll like daughter. The people of the household lovingly named her Ababat Kaur. The connotation of Ababat is related to the service of others...it is related to

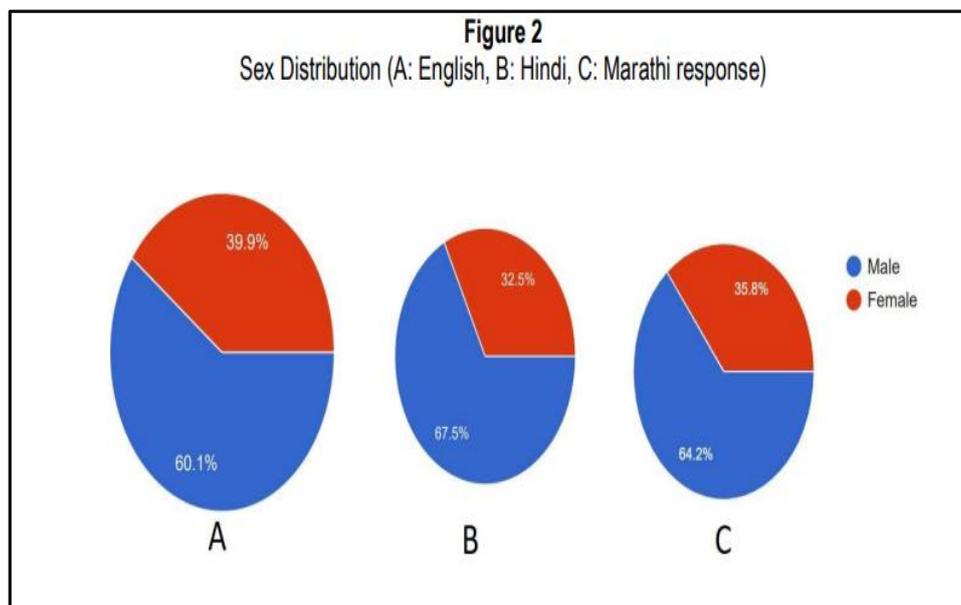
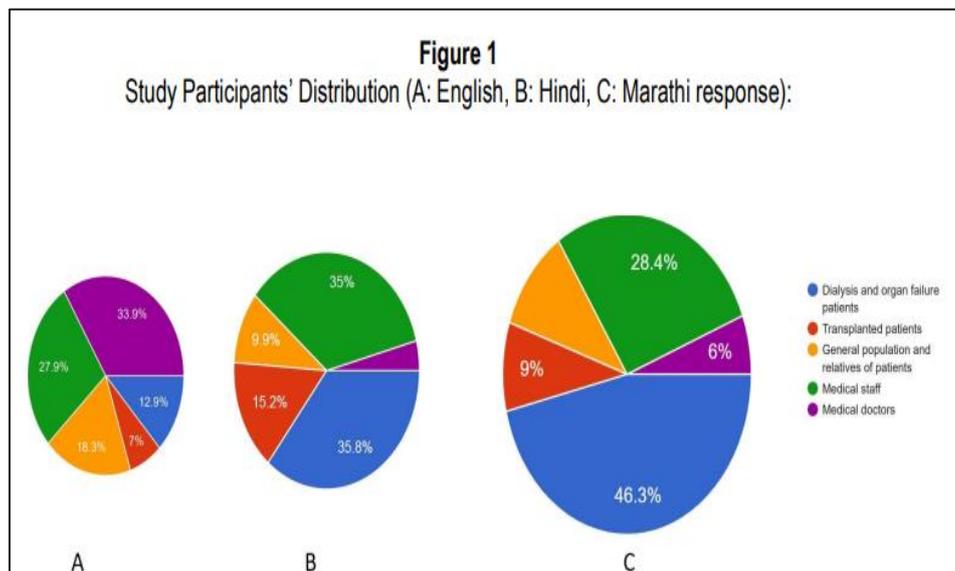
ameliorating the sufferings of others. When she was only thirty nine days old, she left this world. But Sukhbir Singh Sandhu ji and his wife Supreet Kaur ji, their family took a very inspiring decision. And the decision was...Organ Donation of a daughter who was thirty nine days only.

In our country, selfless charity, Parmarth has been placed so high that people do not hesitate to donate their all for the happiness of others. That's why since childhood we are narrated the sagas of Shivi and Dadhichi, who sacrificed their mortal selves.

Friends, in this era of modern medical science, organ donation has become a very important means of imparting life to someone. It is said that when a person donates one's body after death, it creates a possibility for eight to nine people to get a new life. It is matter of satisfaction, that today awareness about Organ Donation is also rising in the country, In the year 2013, there were less than five thousand cases of organ donation in our country; but in 2022, this number has increased to more than fifteen thousand. People who have done organ donation, their families, have actually accomplished a lot of Punya! ¹⁵.

VI. Conclusion

This survey helps us in landscaping the current knowledge and attitude of a diverse group of people right from patients to primary health care providers to the medical fraternity. A significant knowledge gap exists, especially in rural settings, and measures are required to overcome this barrier. We also noticed that Mann ki Baat proved to be an effective way to create awareness and boost existing knowledge about organ donation.



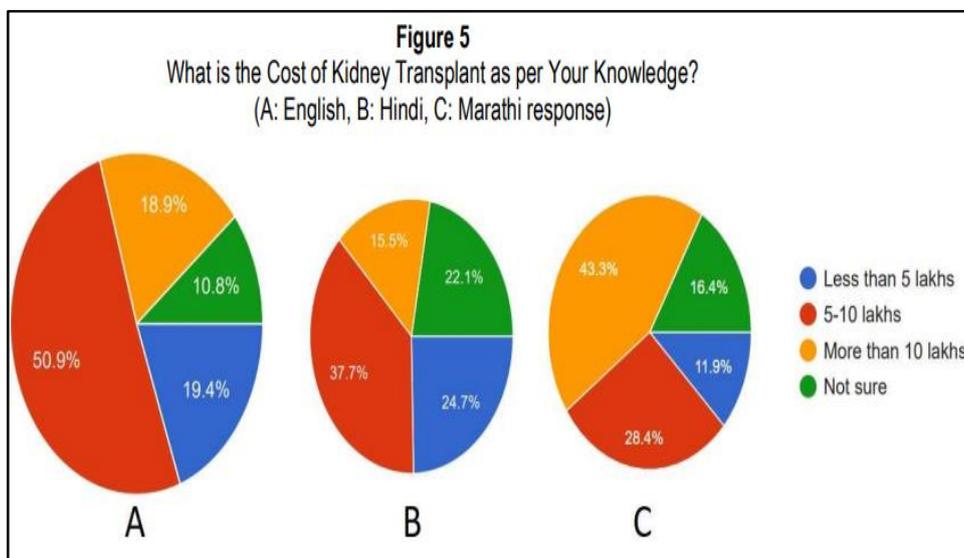
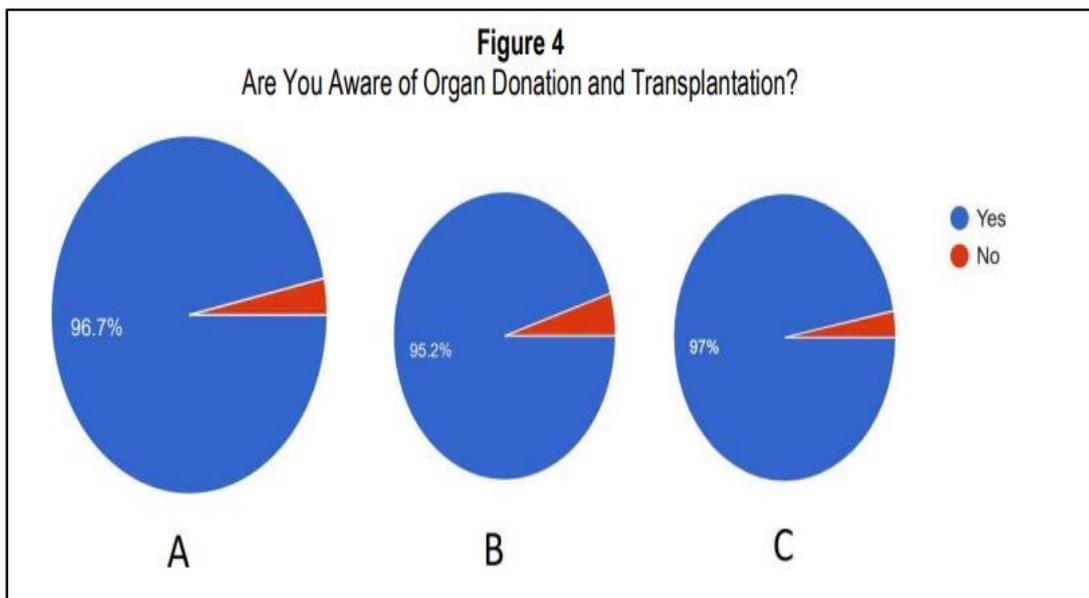
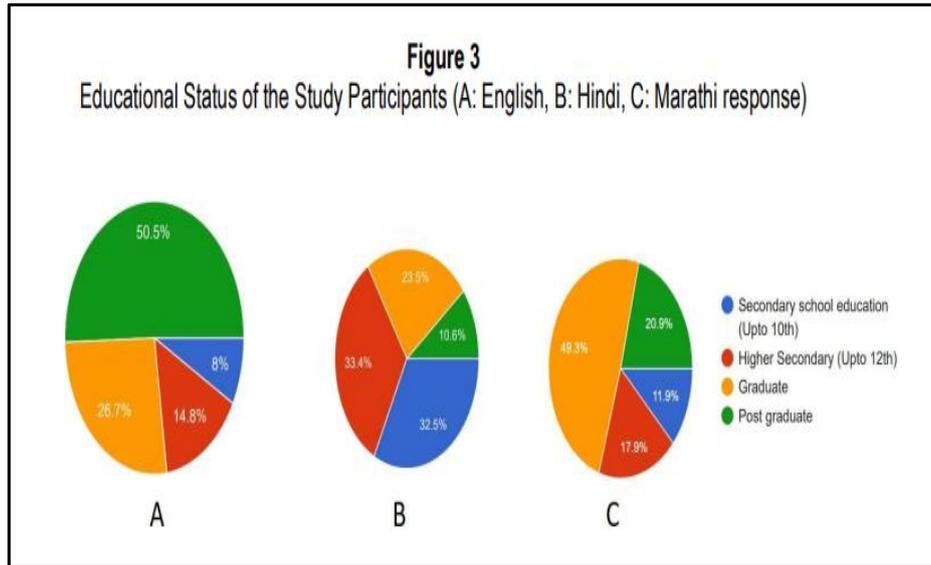


Figure 6
Are You Aware That It is Possible to Donate Organs after Death to Help Save Someone Else's Life?

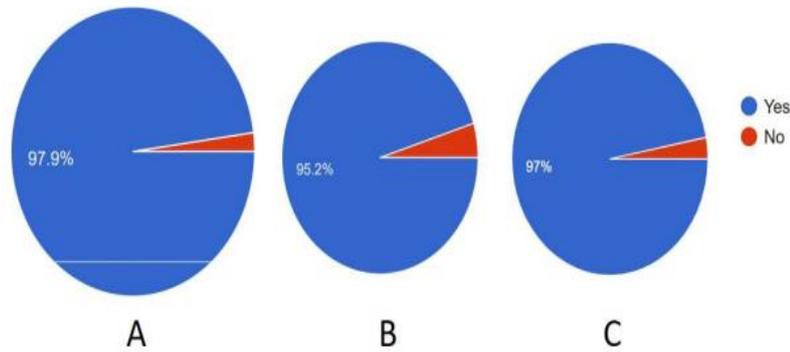


Figure 7
Have You Heard of Recently Prime Minister (PM) Modi Speaking on Organ Donation and Transplants in the 99th Edition of *Mann ki Baat*?

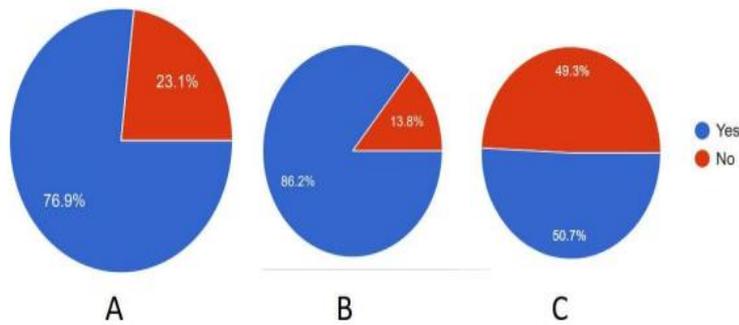


Figure 8
Did the Recent Episode of *Mann Ki Baat* by the Prime Minister Increase Your Awareness and/or Willingness to Become an Organ Donor?

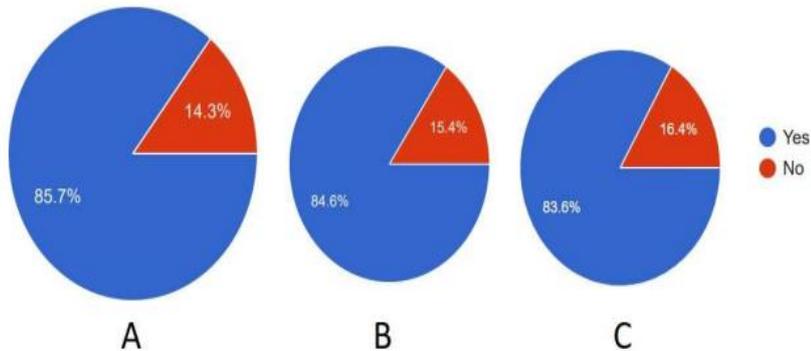


Figure 9
How many organs one can donate after being declared brain dead?

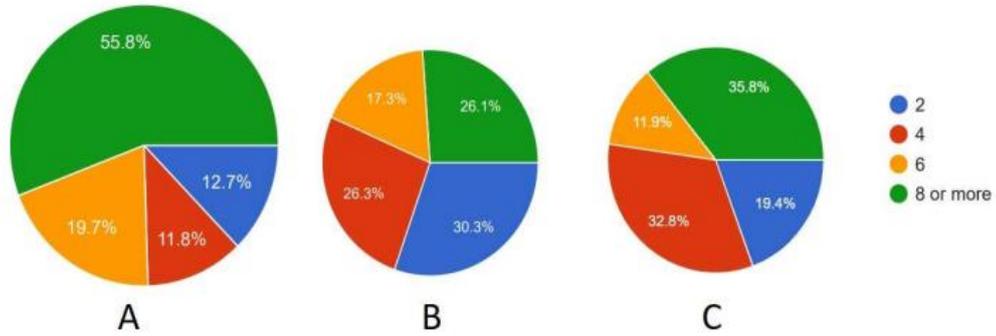


Figure 10
What Was the Age of the Youngest Deceased Donor in India as Mentioned by PM, Modi in *Mann Ki Baat*?

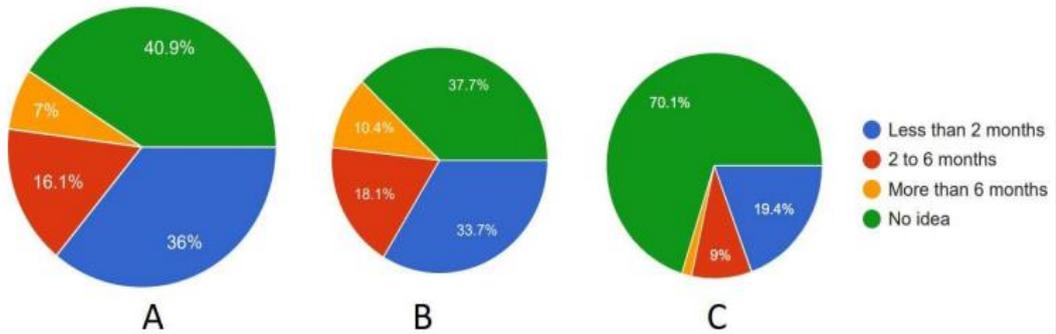


Figure 11
Do You Agree That One Nation One policy and No Requirement of Domicile Certificate for Organ Donation as Envisioned by PM Office Will Change the Scenario of Organ Donation?

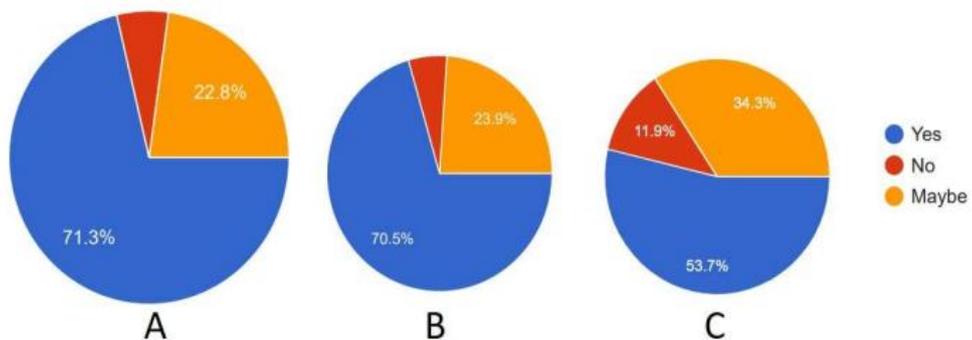


Figure 12
Do You Think That an Additional Column of Mandatory Reporting of Brain Dead (Yes/No) Should be Included in the Death Certificate?

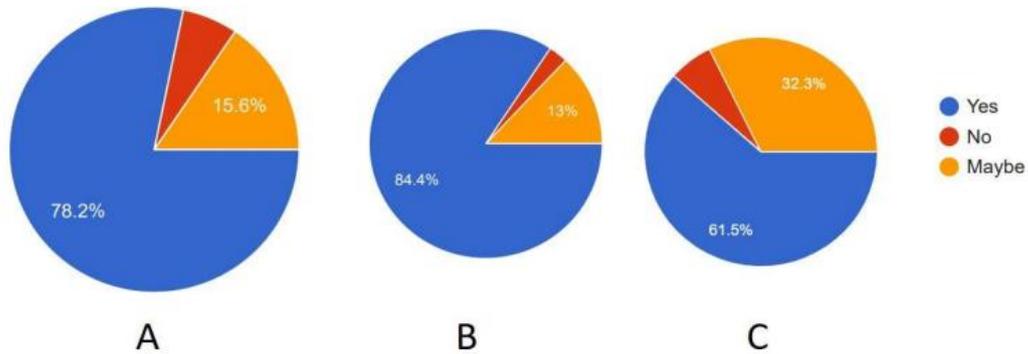


Figure 13
What Should the Family of Organ Donors Expect from the Government in Return for Organ Donation?

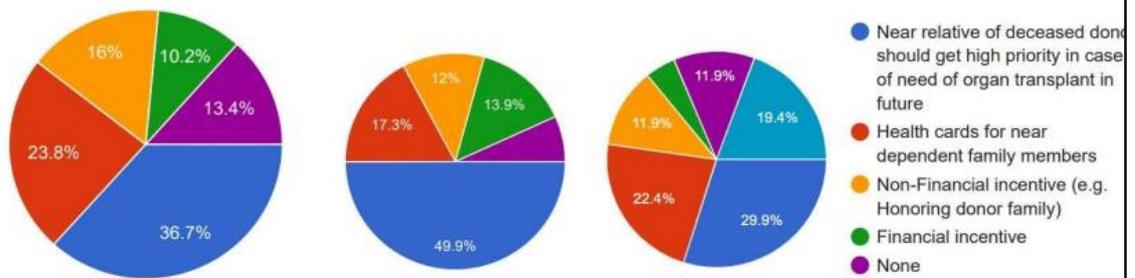


Figure 14
What Should be the Way Forward for Promoting Organ Donation Awareness Drive?

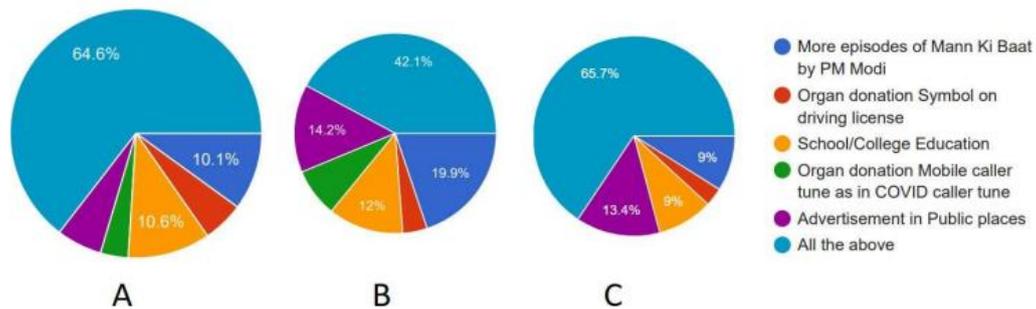


Figure 15
Should Women/Girls and Children Be Given Priority in Deceased Donor Organ Allocation Process?

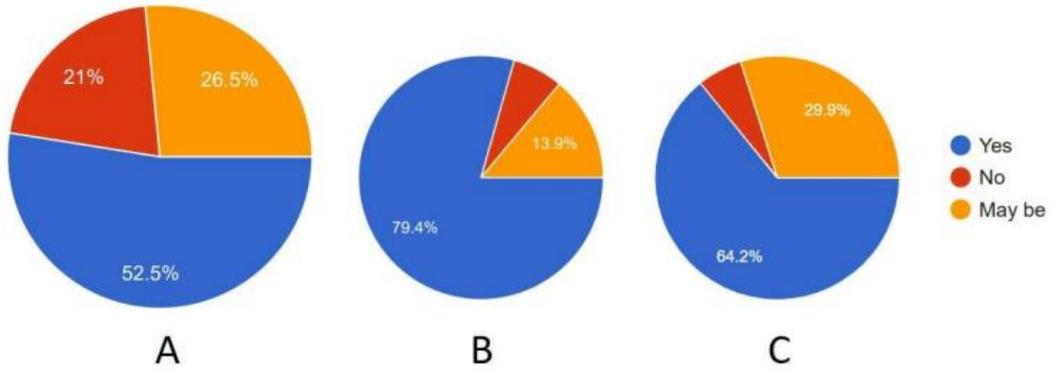


Figure 16
Do You Think Organ Allocation Process is Transparent?

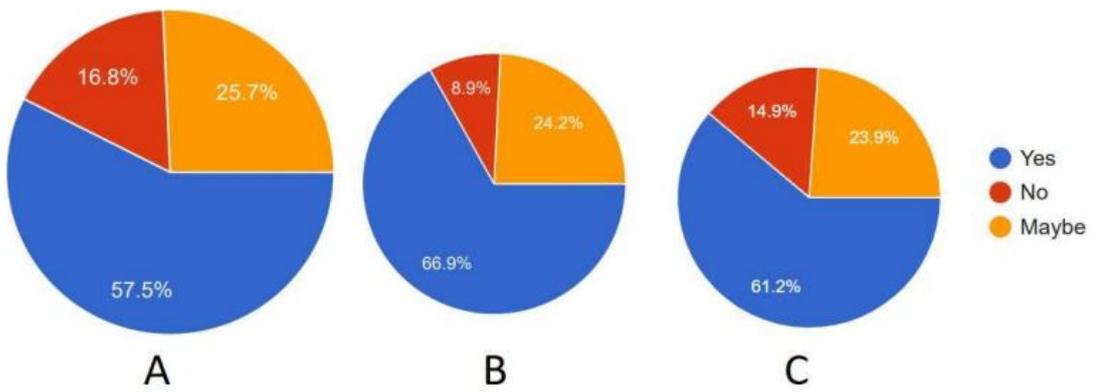
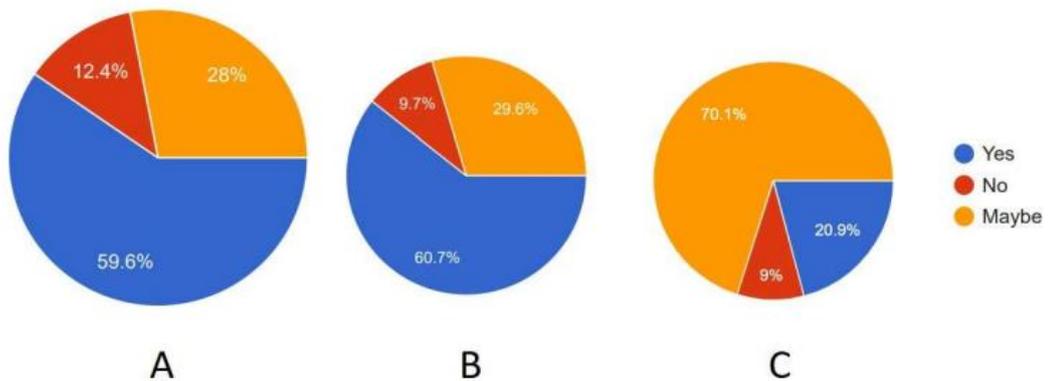


Figure 17
Is Organ- Tissue Donation and Body Donation Is Possible Simultaneously?



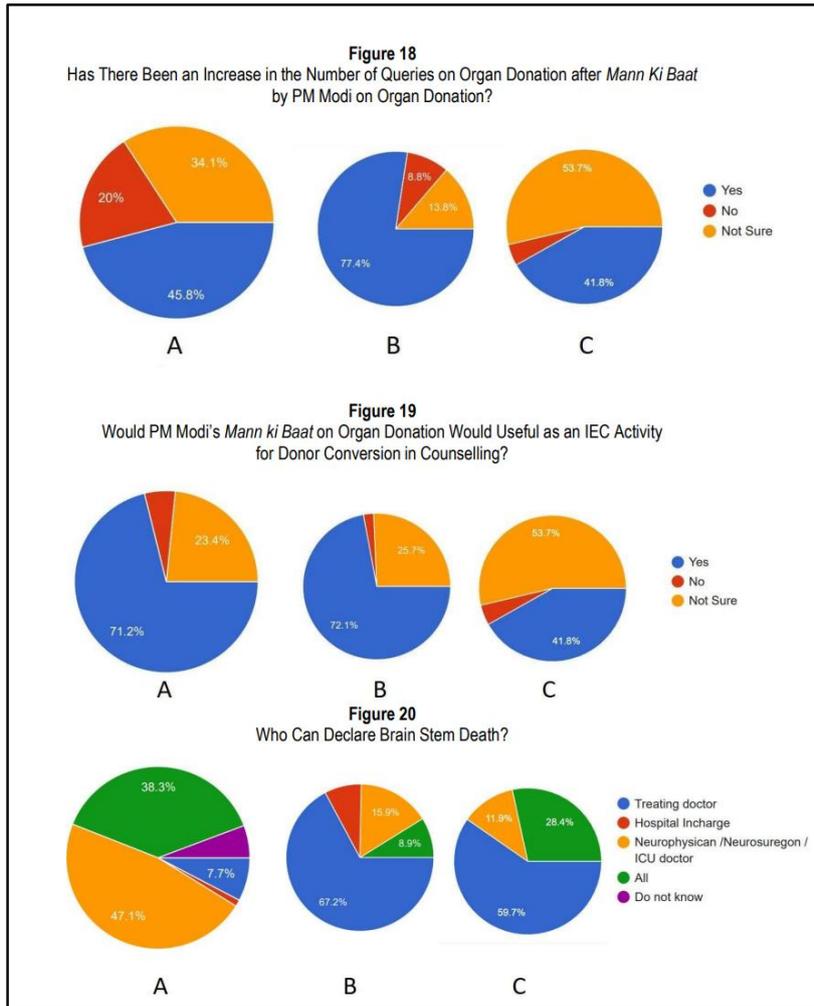


Fig 21. Organ Donation Pledge certificate Issued to Health workers by Ministry of Health & Family welfare, GOI. (An Initiative by Ujjain, District Health worker to Inspire for Organ donation).





Fig 22. In 99th episode of Mann Ki Baat, PM speaks of organ donation, hosts kin of donors¹⁵

VII. Recommendation:

In 99 th edition of Mann Ki Baat, honourable PM have mentioned thousands of people who dedicate their lives in the service of others. There are many people who spend their entire pension towards the education of daughters...some dedicate their whole life's earnings for the environment and the living beings. In our country, selfless charity, Parmarth has been placed so high that people do not hesitate to donate their all for the happiness of others. That's why since childhood we are narrated the sagas of Shivi and Dadhichi, who sacrificed their mortal selves.

In this era of modern medical science, organ donation has become a very important means of imparting life to someone. It is said that when a person donates one's body after death, it creates a possibility for eight to nine people to get a new life. It is matter of satisfaction, that today awareness about Organ Donation is also rising in the country, In the year 2013, there were less than five thousand cases of organ donation in our country; but in 2022, this number has increased to more than fifteen thousand. People who have done organ donation, their families, have actually accomplished a lot of Punya!

Conflict of Interest: Nil

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