ORIGINAL ARTICLE

Development and evaluation of a user friendly android application for advocacy of "Organ Donation" among residents of Western Rajasthan, 2022

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Abstract

Introduction: Organ donation is either when a person allows healthy transplantable organs/tissues to be removed after death, or when the donor is alive. Digitization in various aspects of healthcare is replacing humans, eliminating biases and judgement errors. The use of an android application reduces subjectivity in need assessment, accessing basic information and contacting the right facilities to register for organ donation. **Objectives:** To develop an android application to increase awareness among participants. To assess knowledge, attitudes and practices related to organ donation through the application. To evaluate satisfaction levels regarding the android application. **Methods**: A cross-sectional study was conducted among 384 participants of urban and rural areas of Pali district over four months. A predesigned pretested questionnaire was used for data collection by trained volunteers and analyzed using Epi info (version 7.2). **Results**: The study was conducted among 192 urban and 192 rural participants of Pali district whose average age was 27.5 years in urban and 24 years respectively ,60.2% were females ,29.2% were married, 96% belonged to Hindu religion and 43% were medical students .Although 82.8% of the participants had heard about organ donation only 17.2% had pledged to donate organs. The rural and urban differences were marked stating religion as a determinant of their attitude for organ donation (p-value 0.009), that infants and elders could not donate organs (p-value 0.014), that organ donation was costly (p -value 0.00), that doctors should not advocate organ donation (p-value 0.014). The median agreement was above 5 on the Likert's scale regarding the application being better than print media, increasing insight to organ donation and giving a sense of social responsibility. **Conclusions**: Awareness about organ donation is marred by myths, but the community had a positive attitude to use the application for increasing awareness levels.

Keywords

Attitude; Knowledge; Organ Donation; Android Application

Introduction

Digitization has a very important role in various aspects of healthcare and health education replacing humans and eliminating biases and judgement errors. Today we are witnessing a transition in the use of digital applications in many aspects of health care.

The use of an android application can reduce the subjectivity in both need assessment and in making use of the application to keep basic information on important parameters of organ donation in providing some basic protocols to register for organ donation among those interested. The issue of organ donation is a multifactorial and complex one, involving legal, ethical, medical, organizational, and social factors(1).

Living organ donation involves either donating one kidney or part of liver, after natural/circulatory or cardiac death only tissues and after brain death, solid organs can also be

donated(1). A single person can save up to 8 people's lives and even 9, if the liver is split under ideal circumstances. Via tissue donations, over 50 lives can be dramatically improved by just one donor. All it takes is a signature on an organ donor card. Yet, Organ shortage is a global problem, but India lags far behind the western world(1).

In India, Transplantation of Human organs Act was passed in 1994 , which was amended in 2011 to widen the donor pool and allowing swapping of organs(2). In 2014, transplantation of humans organs and tissue rules were passed. Organ commerce is a punishable offence in India(2).

In a population of about 1.3 billion, the organ donation rate is 0.08 per million population(3). Majority of organ failure patients die while on the waiting list for lack of timely availability of organs. Only 5% of all patients with end-stage kidney disease undergo kidney transplantation in India.

In India, study of human anatomy by MBBS doctors is for 2 years, which requires use of a cadaver and even the advanced operations can be learnt using cadavers by senior doctors.Yet, rather than 4 to 6 students per cadaver ideally , there are 20 to 30 students working on one. Even 28 years since the country passed the act, only kidney donations by live donors are in vogue and cadaver donations are still very few(4). There is a significant gap in knowledge with regards to the concept of cardiac/circulatory death and brain death, amongst the doctors as well as the masses. Certification and declaration of brain death is mandatory in transplant hospitals and in non-transplant organ retrieval centres registered under the Human Organs Transplant Act, 1994(5). Yet, at some hospitals the doctors keep the patient on the ventilator as long as it is possible and brain death declaration is low rather than negligible.

Fatal deaths due to RTA in India is 1,42,485, one RTA accident occurs every minute and one life is lost every 3.7 minutes- 67 percent of them are brain dead. If all of them become potential donors, considering one organ donation saving 9 people, 8,59,176 lives could be saved, according to MOHAN foundation(3).

One of the greatest roadblocks to organ donation is the refusal of family consent. Even if the organ donor is registered, if there is no family consent, deceased organ donation cannot be performed(5). Myths and misconceptions along with a general lack of awareness and strong cultural and religious beliefs add to the low percentage of organs donations(6). Practice of "Opt in" strategy rather than "opt out" like France in India is also a contributing factor(7).

Practices such as discussion of organ donation with attorney during discussion of will or health care proxies or advance medical directives, or primary health care physician non judgmentally asking organ donation status of the patient, corporations talking about organ donation with their employees while discussing medical and retirement benefits and providing significant benefits to those who have a donor card are lacking in the country(8). More support groups that offer peer –based support for pre transplant and post transplant patients must be established.

As per recent reports, Tamil Nadu state tops the list; with an organ donation rate of almost 1.3 per million population in 2012(9). Trained staff with adequate infrastructure, formation of green corridors significantly increased organ donation rates(10). Indeed lack of awareness of organ donation is significant among the population and modern technology can be put to use to bridge this gap . This study is an attempt to do the same in the area around our medical college and its affiliated health centres.

Aims & Objectives

1. To develop an android application which will help in increasing awareness on organ donation among residents of Pali district, Western Rajasthan.
2. To assess the current knowledge, attitude and beliefs on organ donation and share the android application which will connect them to established governmental as well as NGOs working in the field of organ donation.
3. To evaluate the satisfaction levels of the participants regarding the android application on organ donation

Material & Methods

Study design: Cross –sectional study

Study setting: 192 residents in the catchment area of District Hospital/ Urban Health and training Centre (UHTC) and 192 residents in the catchment area of Rural Health Training Centre (RHTC) of Government Medical College Pali , Rajasthan were included in the study .

Inclusion criteria

1. Should be above 18 years of age
2. Should possess a smartphone
3. Shows interest in knowing more about organ donation .
4. Is willing to share information with three other residents .

Exclusion criteria:

1. Persons or their families who have undergone transplantation
2. Persons working with or related to organ donation centers

Study period: 6 months

Sample size: A total of 384 participants were taken using random sampling method keeping power of study at 80% and 50% prevalence for correct knowledge on organ donation.

Study sampling procedure: The participants were selected following a random sampling method till sample size was achieved from among the households within 10 kilo metres of the health centres.

Data collection: Data was collected by the Principal Investigator and trained volunteers after development of the application .The application was developed by three students of Department of Computer Science, Jaypee Institute of Technology, Noida. A structured questionnaire built into the application and was used to collect data from respondents with respect to their pre and post use of the application .The questionnaire was field tested among 20 participants before finalizing. All respondents were interviewed on 48 questions on demographic details, knowledge ,attitudes and beliefs regarding organ donation and 10 questions measuring satisfaction levels regarding the use of the application developed by the engineering students .Data on various socio-demographic variables, knowledge, attitude and practices with regards to organ donation was collected before sharing information regarding organ donation and thereafter again after one week of providing them the application link . Data was entered and analysed using Epi Info (version 7.2) and MS Excel software (version 16) . The Likert 5 point scale was used to determine satisfaction levels regarding the android application.

Human subject protection: The participants were explained the voluntary nature of their participation and rights to withdraw at any time. They were explained about the need for the study and were informed that there will be no penalty for withdrawing from the study. A written informed consent in vernacular language was taken from each participant .

Development of the application :

The application was over the platform of android studio. The developers created their own logo and icon. The app had Frequently Asked Questions (FAQs) written in both Hindi and English language making it easy for the people to read them in their choice of language.

The following is the link to the application:

GMCP ORGAN DONATION AWARENESS.apk

Results

Demographic details : The study was conducted among 384 participants (192 from urban and 192 from rural areas) of the district whose average age was 27.5 years in urban and 24 years of which 60.2% were females and 29.2% were married 96% belonged to Hindu religion and 43% were medical /nursing students .(Table 1) .

Among all data regarding the key beliefs of the respondents about organ donation revealed that majority felt the treating doctor should ask and know about the patient status with regards to organ donation (70%),also (66%) felt that opt out strategy is good, 56% believed that body for cremation will be mutilated or disfigured due to organ donation but only 28% believed that their religion forbade them to donate organs .(Figure 1)

The respondents felt that the major ways of promoting organ donation in decreasing order are giving free health treatment(21%) ,monetary benefits (10%)and awards (8%) or a combination of all the above (61%).(Figure 2)

The three points on which the agreement among respondents was maximum were that the application was better than print media giving a fresh insight into organ donation , it gave them a sense of responsibility for organ recycling and because of its user friendly interface they will recommend the application to others.(Figure 3)

Discussion

As per the National Organ and Tissue Transplant Organization (NOTTO), the PAN-India deceased organ donation rate is at 0.34 per million population (PMP) which stands the lowest in the world(11). While 1.8 lakh people suffer from renal or kidney failure, only 6,000 renal transplants are conducted annually. The reasons cited behind the shortage of organ donation in India were limited awareness, lack of infrastructure, lack of family consent due to prevalence of myths and misconceptions(11).

This cross sectional study done in Western Rajasthan reported that although 83% knew about organ donation only 17% had registered for being a donor . These findings were similar to another study by Sarweswaran Get al in Puducherry , South India(12).

One of the significant knowledge points which needs urgent attention is that the role of the family in a “Brain death ” situation is vital as the donor is on the ventilator and the family has to make a choice (13). Taking a pledge for organ donation by anyone who is above 18 years of age and keeping the family informed about it is imperative. Any person who is at least 18 years old can promise to donate their organs and tissues. Cornea, skin, bones can be donated 6-10 hours after the heart has stopped but majority of the organs are donated after brain death.

In our study also 78.9% felt family should give consent for ‘after death’ organ donation and 66% of the respondents were in agreement with the ‘opt out strategy’ which means that they wanted to donate organs unless otherwise specified . This is similar to the findings of the National Survey of Organ Donation Attitudes and Practices of America done in 2019 where the respondents aged 18-34 years were more likely to want their organs donated (57.2%) but 31.6 per million had registered in USA as compared to just 0.86 per million in India(14).

In our study most respondents said they would donate certain eligible organs while living to a family member (55.2%) than to a friend (20.1%) or stranger (44%) . This is similar to a survey done in Delhi NCR region by Organ India foundation in 2014 which stated that 86.0% would donate to family member ,to close friend (75.7%), but fewer would donate to an acquaintance (54.6%) or stranger (45.5%).(15)

Beliefs about organ donation were divided into beliefs about the benefits of donation, concerns about donation,

and the role of religion and law /legislation in this practice.(12)Our study showed that 84% believed that organ donation can save someone's life and hence should be promoted 28.4% of the respondents also believed that religion forbids them to donate organs, 71.6 % believed that diabetic/ hypertensives cannot donate and 68% were not aware of laws /legislations about organ donation.

As per a West Bengal study conducted in 2019 by Paul S et al interestingly, 6% of the participants had already signed form or card for cadaveric donation in the future and 12% had seen people donated organ in their community(16). With time and medical technological advances the practice of organ donation is becoming more common.

The respondents in our study were aware that eyes, kidneys, lungs and heart were commonly donated organs but few knew about blood and bone marrow . According to NOTTO, out of 12 donatable organs, participants were aware about only three and the most common organ mentioned by them was eye(14). Similar findings were reported by other studies done by Dasgupta A et al and Manojan KK et al done in Kerala and West Bengal respectively. (17,18)

Even in the United states though 95% of the population supports organ donation only 58% are registered donors as per the Florida health blog.(19) In many countries the law is to show your willingness to donate your organs on your driving license without burdening the family to take a decision in case of sudden death This step however has not been taken in India yet and 45.3 % of our respondents wanted to "think about it" rather than take a decision to commit to organ donation and take the pledge .

Most respondents wanted free health treatment (21%), monetary benefits and awards or a combination of these (61%)in our study . Incentivized donation, i.e the state offering incentives to promote individuals' willingness to donate. In a report published in 2011, the UK Nuffield Council on Bioethics for example claims that the state plays a role in encouraging individuals to donate their organs(20). The research report of Organ India states that brain death as a form of death is not widely understood or recognized by the public.(15) Also there is hesitation on the part of the medical fraternity to certify brain death. This has to change if the organ donation rates have to be increased. Lack of training for intensive-care unit personnel to maintain brain dead person, is also a constraint according to a number of doctors surveyed(13) . A big percentage of doctors are unaware of the process as a whole and about the idea of brain death since it is not part of their formal education curriculum(13). In our study, also respondents were confused about brain death where 43% mistook coma for brain death and were unaware that a panel of four specialists are needed to declare someone as 'Brain dead' in India . More people from rural 14.6% versus urban 8.3% felt that money and political power can help in being on top of the list to receive organs.

MOHAN foundation Organ secure and Nevon foundations and some others have come up with android friendly applications spreading awareness on Organ donation and connecting donors with seekers in an ethical way(3). Most applications aim at linking the donors or wanting to be donors to the seekers without telling the details of each other just by passing the urgent message requests from recipients to the donors. The donors and the seekers will register through the app by filling personal details along with uploading a donor card and medical reports. The applications are handled thereafter by an authorized organization for matching donors with seekers.

Conclusion

Our study showed that still in the community there are a lot of myths about organ donation such as- Organ donation mutilates/disfigures the body, if we donate the organs we will be born without them in the next birth, some religions forbid organ donation and transplantation, once a person becomes an organ donor, he/she cannot change his mind, and if the family agrees for donation, the doctor will not try hard to save the patient. There is confusion among the rural population between concept of brain death, coma and cardiac death. Regarding receiving donated organs, it is believed that you have to be rich or a celebrity to move up the recipient list quickly. Another common misconception is that donors and their family will have to pay money to the hospital for getting organs donated and there will be a delay in the funeral of the donor. People also believe that age, illness or physical defects can keep a person from being an organ donor. The android application created in this project has attempted to address these issues/ myths in the frequently asked questions section of the app.

Recommendation

Interface awareness sessions in schools, colleges, offices, social clubs, which focus on sensitizing the public about organ donation to save lives, is the need of the hour and trained medical students/ Interns College can take up this initiative. There might be certain misconceptions and sociocultural beliefs regarding organ donation, which needs to be addressed through "awareness campaigns" involving digital dissemination of information, ASHAs and other rural and urban frontline workers who are closer to the community to reach the masses.

Sharing personal experiences of those who donated and those of the recipients, making short public health documentaries or films of awareness featuring eminent personalities of the society can also improve awareness and allay myths and misconceptions regarding organ donation.

The procedure for registration of organ donation is complicated, hence simplification of the process and availability of registration facility at lowest possible level of health care need to be done.

Training of the intensive care unit staff about brain death and organ donation is the need of the hour. In fact, it is important that Organ Donation guidelines and legal aspects be added to the curriculum of the medical undergraduates. User friendly applications like the one mentioned can help in close at hand information for action It bridges the gap in knowledge and helps in connecting potential donors to the right registering agencies /health centers especially the rural population. Information through these apps should have FAQs in local languages to dispel myths and misconceptions.

Disclosure of interest: The authors declare that they have no competing interests.

Limitation of the study

Limitations of our study were that being cross-sectional in nature the association between awareness regarding organ donation and sociodemographic factors was precluded. Reasons for lower practice of registration for organ donation will need more detailed studies. However, the nature of attitude of the community toward organ donation and the positive response to the use of the android application were important strengths of the study.

Relevance of the study

This android application has greatly helped in increasing awareness on organ donation and its use has connected residents to credible organ donation sites in Pali district of Western Rajasthan.

Authors Contribution

All authors contributed equally to the study.

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Tables

TABLE 1 DEMOGRAPHIC CHARACTERISTICS OF RESPONDENTS OF WESTERN RAJASTHAN ,2022

Variables	Total (n=384)	Urban Area (n_1=192)	Rural Area (n_1=192)
Age(years)	25.71±9.799	27.54±10.316	23.88±8.865
Gender (Female)	231(60.2%)	80(41.7%)	151(78.6%)
Marital Status			
Single	272(70.8%)	116(60.4%)	156(81.3%)
Married	112(29.2%)	76(39.6%)	36(18.8%)
Occupation			

Variables	Total (n=384)	Urban Area (n_1=192)	Rural Area (n_1=192)
Students	174(45.3%)	100(26%)	74(19.2%)
Others (unemployed, housewives, shop keepers, self- employed , government jobs)	210(54.6%)	92(24%)	118((30.7%)
Religion			
Hindu	369(96.1%)	183(95.3%)	186(96.9%)
Muslim	10(2.6%)	6(3.1%)	4(2.1%)
Christian	2(0.5%)	1(0.5%)	1(0.5%)
Other	3(0.8%)	2(1.0%)	1(0.5%)

TABLE 2: KNOWLEDGE REGARDING ORGAN DONATION AMONG RESPONDENTS OF WESTERN RAJASTHAN, 2022

Variables	Total(n=384)	Urban(n_1=192)	Rural(n_2=192)	p-Value
Have you ever heard of the term "Organ Donation"?				
Yes	318(82.8%)	171(89.1%)	147(76.6%)	0.001
Does your religion allow organ donation?				0.000
Yes	221(57.6%)	117(60.9%)	105(54.7%)	
Don't Know	101(26.3%)	66(34.4%)	35(18.2%)	
For donation after death, who should give consent?				
Family	303(78.9%)	143(74.5%)	160(83.3%)	
His spouse	73(19.0%)	48(25.0%)	25(13.0%)	
His friends	8(2.1%)	1(0.5%)	7(3.6%)	
Who should make such decisions about organ donation in case of unclaimed dead bodies?				
Medical colleges/doctors	172(44.8%)	74(38.5%)	98(51.0%)	
Police	38(9.9%)	12(6.3%)	26(13.5%)	
Charitable organization	29(7.6%)	14(7.3%)	15(7.8%)	
A judge	123(32.0%)	91(47.4%)	32(16.7%)	
No One	22(5.7%)	1(0.5%)	21(10.9%)	
What organs can be donated?				
Eyes	153(39.8%)	93(48.4%)	60(31.3%)	
Kidney	111(28.9%)	61(31.8%)	50(26.0%)	
Heart	116(30.2%)	66(34.4%)	50(26.0%)	
Blood	97(25.3%)	61(31.8%)	36(18.8%)	
Lungs	29(7.6%)	3(1.6%)	26(13.5%)	
Liver	53(13.8%)	19(9.9%)	34(17.7%)	
Bone Marrow	37(9.6%)	12(6.3%)	25(13.0%)	
Skin	12(3.1%)	3(1.6%)	9(4.7%)	

TABLE 3: ATTITUDES REGARDING ORGAN DONATION AMONG RESPONDENTS OF PALI, WESTERN RAJASTHAN, 2022

Variables	Total(n=384)	Urban(n_1=192)	Rural(n_2=192)	P Value
Should organ donation be promoted?				
Yes	345(89.8%)	189(98.4%)	156(81.3%)	
Have you ever donated an organ?				0.031
Yes	34(8.9%)	23(12.0%)	11(5.7%)	
Why is organ donation done ?				
To save someone's life	323(84.1%)	160(83.3%)	163(84.9%)	
As a "responsibility"	16(4.2%)	6(3.1%)	10(5.2%)	
Out of compassion/sympathy	33(8.6%)	21(10.9%)	12(6.3%)	
For money	12(3.1%)	5(2.6%)	7(3.6%)	
Your attitude towards the possibility of your own organs being used for donation?				
Would definitely want to donate irrespective of circumstances	54(14.1%)	26(13.5%)	28(14.6%)	

Figures

FIGURE 1 BELIEFS REGARDING ORGAN DONATION (N=384)

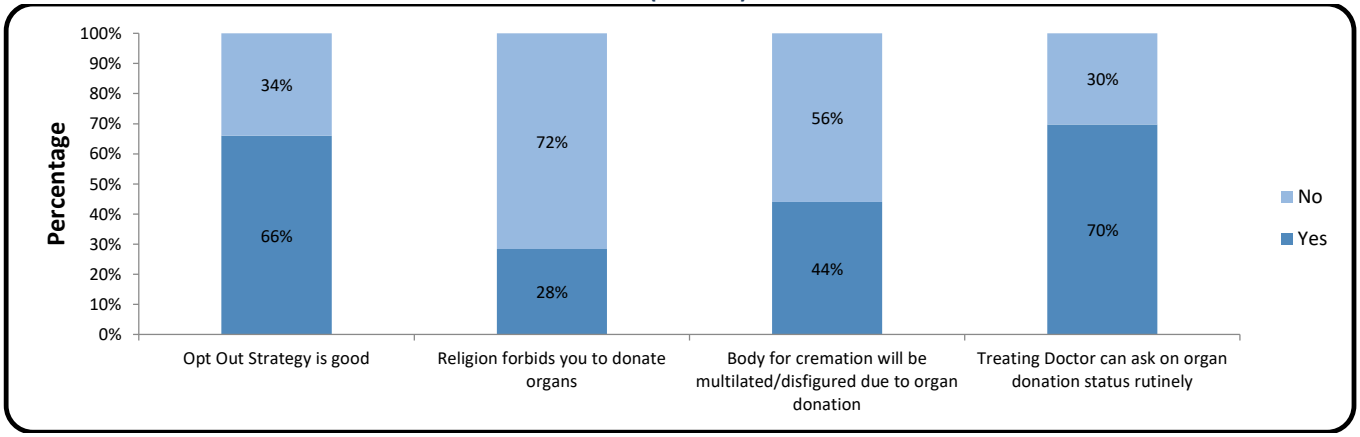

FIGURE 2: MEASURES TO PROMOTE ORGAN DONATION AS PER RESPONDENTS(N=384)

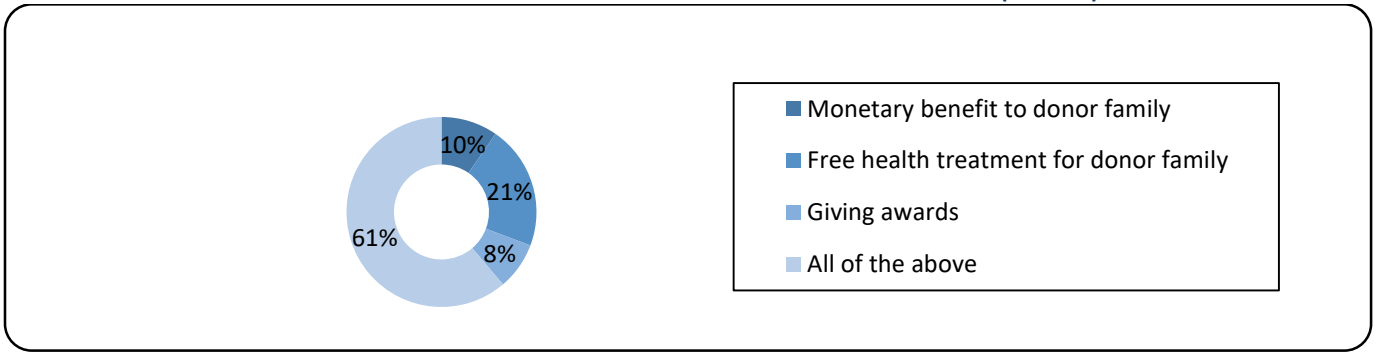

FIGURE 3. SPECIFIC CRITERIA REGARDING SATISFACTION WITH THE DEVELOPED ANDROID APPLICATION AS PER 5 POINT LIKERT SCALE