



Perception of youth on organ donation: A qualitative study

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Abstract

Background: Organ donation and transplantation are regarded as among the most significant advances in modern science, having given several patients a new lease on life. The study's goal was to gather evidence on the perception of organ donation among the youth population.

Methods: The semi- structured interviews were conducted during January-February 2022 in Chandigarh India. A total 20 participants were included in study. The collected data were analyzed by manual thematic analysis.

Result: We found that participants had adequate knowledge and had willingness towards organ donation. Further few participants expressed reliance on family, community and religion, however were not in favor of organ donation. The dilemma towards perception on organ donation remained with the youth.

Conclusion: A large proportion of participants were opposed to organ donation. Family, community, and religious beliefs all influenced the unfavorable attitude and restraints.

Keywords: organ donation, transplantation, modern science

Introduction

The need for organ transplantation has surged in recent decades, while the number of donors has stayed largely stable. Some researchers have looked into the opinions and feelings elicited by the donation process in order to uncover elements that may prevent organ donation consent being granted. One important reason has been mentioned: family resistance to consent to organ donation. Because the transplant team is unaware of the emotional needs of organ donor families and provides insufficient information to families regarding brain death and organ donation processes, relatives of the deceased may make an unwise decision. Organ transplantation is regarded as one of the most significant advances in modern science, having given several people a new lease on life. Worldwide, organ transplantation saves thousands of lives. The problem of organ donation is advanced and multi factorial, involving medical, legal, ethical, structure and social factors.¹

Significance of Study

According to surveys, the religious, social, and cultural beliefs of non-family donors have a significant impact in the procedure.² there are frequently disparities between the ethnicity of the organ donor and the ethnicity of the organ recipient due to a lack of deceased donors. When a receiver is matched with a donor from the same ethnic group, the odds of long-term survival are increased. Furthermore, donor families' challenges in making a decision are exacerbated by their confidence in the body's integrity after death, concerns about the proper moment of death, previously unknown preferences about donation, and emotional exaggeration. In addition, the literature has covered socioeconomic and educational levels, age, sex, and altruistic attitudes as determinants impacting family

permission. To our knowledge, to show a concrete influence of religiosity on communicated anxiety in organ donation discussions. It also adds to the growing evidence that religiosity plays an important role in communication contexts. Scholars have long shown that religiosity tempers life anxiety, but very few have examined its role in anxiety during interactions. Part of what may account for its role in this context is the comfort that religious guidance provides in offering scripts for religious individuals' organ donation attitudes. With the ability to fall back on religious edicts as central drivers of beliefs on this front, any anxiety that religious individuals may experience about family members attitudes prior to the discussion disappears once the interaction begins. In India, the Transplantation of Human Organs Act (THOA) was enacted in 1994. Yet the rate of organ donation in India is poor (0.34 per 100 000 population) compared to developed countries. In addition, organ donation following brainstem death is infrequent in India. THOA (1994) defines brainstem death as „the stage at which all functions of the brainstem have permanently and irreversibly ceased“. Attitudes are generally influenced by social and cultural factors. Knowledge, attitude and behavior are the key factors that influence rates of Organ donation. Culture and religion have also been documented to affect the decision-making process of organ donation. Hence, it is crucial to assess the knowledge and attitudes of the general population towards organ donation. In India, published evidence on organ donation is mainly from studies among healthcare workers, patients and college students. However, some research is available about organ donation among the general and rural populations. We assessed the knowledge, attitudes and willingness to donate organs among the general population.⁴ Donation has been slow to take off in India. In northern states the pace has been

sluggish. More alarming is the glaring absence of any attempts to understand the reasons behind this failure. There is a poor organ donation rate -026 per million India. With a 1 per million –donation rate, India would have 1,000 organ donors or 2,200 kidneys, 1,000 hearts, 1,000livers, 1,100 pancreas and 2,200 eyes. At a 2per million donations rate there would be 2,200 organ donors and above figures would double. Then there would be no necessity to undertake living kidney donation. There is need of roughly 200,000 kidneys, 50,000 hearts and 50,000 livers for transplantation each day. Lack of awareness remains one of the leading reasons for such low organ donation rate in India. There are no structured/ focused awareness initiatives or drives to help people understand the what, why, or how of organ donation. Religious beliefs also may be a reason why a family of deceased does not allow for organ donation. The idea of charity and perceptions about donation varies from one community to another. The religious mindset together with the unpleasant experience in the health sector faced by people is detrimental to the improvement of the organ transplant scenario in India Worldwide, organ transplantation saves thousands of lives, the problem of organ donation is advanced and multi- factorial involving medical, legal, ethical, and social factors, the sector of organ donation has concerned from the first beginnings of experimental excretory organ transplantation to the present follow of multiple organ transplantation.

The organ transplantation is an effective medical care for end-stage organ failure and is wide practices round the world. In keeping with WHO; excretory organ transplants are administered in ninety-one countries. Around 66,000 urinary organ donations, 21,000 liver donations and 6000heart donations were transplanted globally. The ethical verdict on organ transplantation is disputable and varying. Therefore, opinions about organ transplantation depend on personal opinions, as well as religious and geographical reasons, and involve economic, emotional and socio-cultural factors, which deserve discussion and study.⁵

Objective of the Study

To identify Perception of Youth across religions Hindu, Muslim, Sikh, Christian communities from Chandigarh India

Methodology

Study Desgin

The qualitative study was conducted using a semi-structured interview guide to learn about the perceptions of the youth population in Chandigarh, India. We chose a qualitative approach to understand visions in order to discover new ideas and individual perspectives, which aids in the development of concepts and makes it an in-depth study for research.

Study area

The study is being conducted in Chandigarh. According to 2014 statistics, the population was approximately 10, 54,686, with a total of 6 donors. (Organ donation rate is 5.7pmp.). According to 2017 No. of deceased organ donation were only 44 lowest as compared to Tamil Nadu, Maharashtra. Only one major hospital deals with organ donation and transplantation, a Postgraduate Institute of Medical Education and Research, and Chandigarh has the lowest donation rate in India when compared to other regions. The rationale for this choice was that it has a low

donation rate and a good number of institutions and universities with a diverse population needed for my study, as I needed more youth population.

Sample population

The study is being conducted on a diverse population in the Chandigarh region and youth were selected between the age of 18 and 30 chosen. According to the National youth policy of India define youth population as those in age group of 15 to 35. The availability of age group between 18 to 30 was more as compared to other age groups, that's why we chose that age group. There were total 6men and 14 women in my research including students and employees those were graduates. The local population was included in the study of four different religion, migrants were excluded from study.

Sampling size and technique

The expected data to be collected around 50(10/each religion) were planned to be conducted, however ended with 20 interviews. The subjects participated in the study were young youth including students and private working employees from four different religions. The reason for focusing on the youth population is that they are a generation of potential and the future of the country, and they may advocate organ donation in a flattering manner in future. The participants were purposively selected on their willingness to be a part of the study.

Inclusive Criteria

Age group 18-30 years.

Person who falls under the four religion – HINDU, MUSLIM, SIKH AND CHRISTIAN & WAS ready to participate in the study

Exclusive Critiera

A person who was under the age of 18 and over the age of 30. Because my study focuses on youth, this age group does not meet my research criteria.

Data Collection Tool

We conducted a face-to-face interview by using semi-structured questionnaire. The interview was started with introduction warm up followed by their opinion about organ donation. The semi- structured guide also covered the other discursive questions on their willingness for organ donation and concerns and conflicts related to organ donation for the. During the interviews, the influencers for their organ donation decision also discussed with few of participant.

Data preparation analysis

All data were hand transcript and was translated in English, we have translated manually and themes were generated category wise in excel sheet. Manual qualitative thematic analysis was done on translated data.

Ethical Consideration

Interviews were conducted in the adequate privacy after taking an oral consent from the population.

Result Interpretation

Basic characteristics of the participants

They were between 20 to 30 years of age group. Male participants were total of 6 and females were 16. Both male and female were youth some were students and others were employees. As per the academic qualification, all of those participants were graduated in different fields of science and

commerce and least participants were pursuing graduation. The observation was ruled out from all the participants' transcripts and the thematic analysis is presented below. A total of four themes are derived which include awareness, family and community beliefs, attitudes and emotions and religious beliefs

Willingness on organ donation

All participants were aware of the word organ donation on asking about the organ donation and would you ready to register for organ donation they felt" it's a good initiative and we can help needy and all participants were of opinion that organ donation will give "new life to others".

"Yes, I will be an organ donor, because I can be helpful to somebody, and this the noble job that's why I want to be an organ donor" (PP1)

Participants have so much interest to be an organ donor, shown their thoughts why they want to make such decision or what thoughts were in their mind for being an organ donor.

"My family has been an organ donor from last past years, and I can be helpful to somebody so why not" (PP2)

On asking about what makes you to be an organ donor and what all do you think before making such decision, all participants were comfortable to be an organ donor one respondent draws attention towards the contradiction of the statement on organ donation that

"Organ donation sounds weird, but acc to me it will set somebody's life and need courage to do" (PP3)

"I want to be an organ donor because it is said that we come on earth without our permission but we can go by giving new life to someone" (PP4)

Barriers from family and community

All participants were ready to register and to donate organs but some were influenced by the society and family members and some participants have to consult their family members before registering. Some of the participants drawn attention towards their approvingly behavior that their family members won't influence and will be ok with their decision to be an organ donor

"My family won't accept my decision and will say no to me, they won't allow me because I have small kid and husband so not going to risk our lives" (PP3)

"If my parents emotionally blackmail me, it would affect my decision" (PP5) *"They will be fine with my decision as they keep SEVA DI BHAVANA"* (PP7) *"No one can influence my decision not even my family member"* (PP10)

One of participant talked about disbelief and misconception in the family and community members that if we donate organs after death, in next birth us will be off without organs. Majority of the participants were opinioned that building such conversation with family organ member would be difficult for them and they will react negatively towards the conversation of donation and some of the participants were opinionated that their family members will react positively to the conversation, will be happy with their decision

"I have heard a lot from family that if we donate eyes" aagle janammei hum aandhe paida honge" (PP3)

"My parents will react negatively to such conversation, they will be like how the donation process will go, will neglect the topic and I don't think I will face any hurdles building

such conversation with them but with community I may face hurdles" (PP6)

"They will listen and might appreciate but don't think will get agree with decision and emotional hurdles will come surely while building conversation" (PP8)

Attitudes, Emotion towards consent and health professional

On inquiring about attitudes and emotions towards the approach of consent for organ donation of their deceased loved ones, few participants said they cannot take decision on that time because of emotional turmoil and some were ready to sign consent on that time. Some participants said that they will sign without a thought and some participants said that they will sign but their other family member opinion also matters and will have to go with their decision whatever it is.

"Firstly, it will be confusing, but later I will agree to sign" (PP11)

"No, I will not sign consent because the person who is dead if he/she ever had expressed the wish then only I will make decision" (PP14)

"Yes, I will sign consent" (PP5)

"Obviously I will consider my family opinion they are elder to me; I respect their decision" (PP9)

Further inquiring about their attitudes and thoughts towards the healthcare professional team when they make such request to you, almost every participant said they are doing good job.

"They are doing good and noble cause" (PP14)

"It's a good thing, they are doing their job" Maybe they are doing right and it depends on situation on that time" (PP10)

And few participants showed negative response towards it

"I will be very angry but later I will manage" (PP17)

"I would definitely feel bad and would be vulnerable on that time, so it's not a good thing"

On inquiring more about the attitude and feeling when their loved ones declared brain dead and team approaches for consent all participant's responses were mixed and unclear towards it

"I will be sad, because I am attached to that person, I will be shattered" (PP1)

"I will feel good because it's a good thing we are saving life" (PP3)

"I will feel differently due to emotional nature of mine that time" (PP7)

Perception on Organ Donation from different religious people

Organ donation is considered as good initiative by all religion.

- Tip of iceberg: looks like this good in every religion towards organ donation.
- Deep iceberg: looks every religion appears to be full with hurdles and negative attitudes towards organ donation.

On asking questions about the religious beliefs towards organ donation and does it affect or influence your decision and will you give importance to religion in regard to deceased organ donation many participants said that it is not allowed in their religion and cannot go against religion, however few said we don't know whether it is allowed or

not but will go for organ donation and few participants said it is nothing to do with religion.

"No, it won't affect my decision because I am not that religious person and really don't know much about it and it's my life my decisions" (Sikh) 6

No, religion won't affect my decision, according to me humanity is first and in religion says to do "SARBAT DA BHALA" (Sikh)3

"No religion won't affect me for this thing" (Hindu)4

"No religion won't affect me in my religion humanity matters" (Hindu) 2 "No religion won't affect my decision" (Christian) 1

"Yes, religion will affect my decision and my parents will give importance to religion" (Hindu) 1

"Yes, it will affect my decision, if religion allowed me to do so I will, yes will give importance to religion is my uppermost thing" (Muslim) 3

"Religion may affect it because we are not allowed to sacrifice our body or give it prior, yes I love my religion and have grown in it so if it's saying no means no in Islam it is not allowed" (Muslim)2

"Yes, because there will be some notes in holy book written by my gurus on organ donation which I don't know (Sikh)4

"Yes, it's not allowed in my religion" (Christian) 2

Discussion

Organ donation is viewed at several levels of belief, including individual beliefs, community beliefs, religious beliefs, and organizational consent. Individual beliefs revealed that there was no lack of understanding regarding organ donation; they were aware of the donation, but their family participation was present and it mattered to them; religious conviction was present, and they were solid in their decision; fear and body integrity were also present. When it came to community beliefs, there was a lack of acceptance of brain death, a mixed response to organ donation, and a lack of communication because there was no discussion about organ donation. When it comes to the most important beliefs, religious beliefs, different religions have diverse perspectives on organ donation. Some religions were willing to participate in the process, while others had reservations about it. The last frame represents an approach to consent because it contains emotions, familial acceptance for the consent procedure, and a strong desire to be with one's beloved. This conceptual framework addresses what makes people hesitant to donate organs in general. This study looked into the issues that could be linked to Chandigarh's organ donation awareness, attitudes, and emotions, as well as family and community beliefs and the most relevant religious beliefs. Four religions were studied using a qualitative method in various parts of the city. The participants were knowledgeable and aware of the importance of organ donation to both individuals and communities. The youth learned about organ donation from social media, newspapers, and television shows. "It's a great cause," participants remarked, adding "it's a delight to save someone's life." They were willing to be on an organ donor list because they wanted to help others. In similar direction, the other studies also assessed the attitudes, family beliefs and religion perception towards organ donation. The present study found that family beliefs and religious beliefs is the main cause to restrict them from participating in organ donation. One more study formed same result on family refusal for organ donation⁷. Another study narrated the

positive attitudes within community and informed discussions with families.⁸ However, several individuals were hesitant about the donation process, not because of their own personal feelings, but because of their family and community's feelings. They stated that they are unable to make decisions on their own and must seek permission from family members, while those who are married must consult with their partners. It has been discovered that family opinion is important when it comes to granting consent to the deceased loved ones. On asking question would you consider your family member opinion while signing consent many participants said "yes" in regard they are elder to us and we have to respect their opinion. A study on elderly discussion reported similar findings⁹. Participants had a strong altruistic attitude about On discussing about the religious beliefs different participants from different religions have different opinion in regards to organ donation whether it is Hindu, Muslim, Sikh, Christian somewhere they have put the religion in forefront against organ donation. The religious issue is still prevalent among the youth generation but some participants were like they can go against religion in regard to organ donation. The results from these participants indicate that most participants were knowledgeable about organ donation and its purpose and benefits to individual and to society. Most of their comments reflected knowledge and positive awareness towards organ donation but few reflected some misconceptions and lack of information in concern to the family and community beliefs. Many participants recommend public awareness and school based educational campaigns that would be helpful in future. The study from turkey also highlighted the religious people are very sensitive about the subject of organ donation.¹¹ A total perception of youth is average towards organ donation there was willingness and positive attitude towards it but still more motivation is required among them to overcome the scarcity of organs. A study from India on college students were conducted revealed that a well-organized approach is required to remove the setbacks that affect the rate of availability of organs.¹²

Conclusion

The study found that participants had sufficient knowledge and awareness regarding organ donation. However, a significant proportion of individuals polled were resistant to organ donation. The constraints were influenced by mainly religious beliefs which further influence the family and community perceptions on organ donation. The well-organized approach is required to raise awareness among the youth about organ donation which is necessary to eliminate the setbacks that affect the rate of availability of donor organs. Findings reiterate the importance of promoting positive attitudes within the community and specific informed discussion within families. The positive influences these factors exert on next-of-kin decisions may be vital maximize donation rates in opt-in systems in India. Although perhaps not the primary reason given for their refusal, our findings show that religiosity plays relatively strong, yet direct, role in influencing the final organ donation status. Despite the fact that all organ and tissue donation is supported by all major religions, individual often cite religious beliefs as their reason for choosing not to donate.

The study of perception toward organ donation is an ongoing Endeavour, when individuals must make a decision of such great importance for themselves and their families, new elements can emerge among their personal circumstances. The influencing factors may remain the same, drastically change, or take on new meanings. The common ground identified as a result of this brief breakdown is a lack of knowledge about the main aspects of donation, as well as a poor representation of the act of donation in some societies.

There is high level of awareness about eye donation, but awareness about another organ donation is poor. The awareness about eligible donors and timing of donation is also poor and this need to addressed in community with the help of active community engagement and awareness from system

Limitation of study

- This a qualitative study so we have not any hypothesis here
- The study was conducted in Chandigarh and so similar kind of study will be more useful from different states of India.

Ethical Clearance

Ethical clearance was provided from department of public health (Parul university) Vadodara Gujarat.

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