

A Cross Sectional Study on Knowledge and Attitudes About Organ Donation and Transplantation in an Urban Population in a Low-Income Country.

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Abstract

Background: Uganda's Health Sector Development Plan (2015/16 -2019/2020) noted that most referrals for treatment abroad were for organ transplant services costing government over 5.6 million US dollars. The government of Uganda has invested in building capacity for Organ donation and transplantation services by training human resource and setting up the infrastructure in Kampala where these services can be accessed. However, there is no information on the readiness of communities and the scientific community to embrace (communities) or undertake (science) organ transplantation in the country. We set out to assess Knowledge and Attitudes about organ donation and transplantation among the urban population in Kampala.

Methods: We conducted a cross-sectional survey among 395 participants from the urban population of Kampala at Garden City Mall, Wandegeya market and Nakawa market 28th May - 7th June 2021. We asked about knowledge about organ donation and transplantation, collected sociodemographic data and did a sentiment analysis of participants' attitudes towards organ donation and transplantation.

Results: The M:F ratio of participants was 1:1, majority (55.9%) of participants were Baganda, two thirds of participants knew about organ donation, 90% of participants did not know of any government policy on organ donation and transplantation. Radio/television was the commonest source of information. The commonest organ donated was the kidney. Overall, there were 94.3% and 93.2% positive sentiments towards organ transplantation and organ donation respectively. The need for stricter laws governing organ donation and transplantation, corruption and fear were the main negative sentiments expressed by participants.

Conclusions: Sensitization of the community is required about government policy on organ donation and transplantation, and this should be communicated through radio/television and social media. There was a positive attitude towards organ donation and transplantation.

INTRODUCTION/ BACKGROUND

Worldwide there is an increased incidence of non-communicable diseases (NCDs). Presently, the NCD epidemic is one of the limitations to sustainable healthy living and is responsible for more deaths than infectious diseases worldwide. NCDs can cause irreversible organ damage which sometimes results in the need for expensive often inaccessible organ transplantation. Uganda is faced with a growing incidence of non-communicable diseases causing organ damage like kidney damage that requires kidney transplant which is not available in Uganda. Ugandans spent over 75 million dollars in 2016 for travel abroad to access organ transplantation services Uganda's Health Sector Development Plan (2015/16–2019/2020) noted that most referrals for treatment abroad were for organ transplant services costing government over 5.6 million US dollars.

In order to reduce on this expenditure and to build local capacity, the government of Uganda has invested in the training of human resource in organ transplant medicine. In addition, government is also investing in provision of the necessary infrastructure for Organ transplant services in Uganda. The infrastructural development currently includes the renovation of Mulago Super-Specialized hospital where installation of equipment to enable conduct of organ transplantation is being undertaken by government.

To successfully set up organ transplantation services in any country one needs to not only have the trained human resource but also the necessary legal framework under which these services can be provided ethically and safely for the protection of the patient and the donor. In Uganda, the organ transplant bill has recently been passed and this stipulates the legal framework that guides the practice of organ donation and transplantation in the country.

However, an organ donation system required to enable implementation of the organ transplant services has not yet been established and is necessary.

Organ transplant services are heavily dependent on the donors of these organs who are healthy individuals living in the community. The community is a key component in ensuring that there are willing donors who are well informed about organ donation and are aware of the availability and the medical possibility of saving lives by organ donation. The attitudes of the community towards organ donation and transplantation practices is affected by people's personal, cultural and religious beliefs as well as media portrayal of the practice. There is also a growing global illegal lucrative organ trade industry which has further compounded organ donation and transplant services and significantly affects the attitudes of the community. A community that is well informed about organ donation and transplant services working within an organized national legal framework is key in ensuring successful implementation and sustenance of organ transplant services in any country including Uganda.

The government of Uganda recently passed the organ donation and transplant bill and is in the process of establishing organ donation and transplant services in Uganda. It is projected that over 75 million US dollars per annum are spent on medical tourism abroad for specialized care, particularly organ donation and transplant. However, despite advances in passing the Bill and the development of the technical expertise of organ donation and transplantation among the health care workers, knowledge and attitudes of the other stakeholders like the community who are key in ensuring that organ donors are available is not known. This study therefore sought to assess the knowledge and, attitudes about organ donation and transplantation among the urban population in a low-income country that is in the process of starting organ donation and transplantation services.

METHODS

The aim of this study was to assess the knowledge and attitudes of the urban community in a low and middle income on organ donation and transplantation in preparation for the development and implementation of organ donation and transplantation services in Uganda.

Study design

A cross sectional survey was conducted using a questionnaire for knowledge, attitudes and perceptions about organ donation and transplantation among the urban community in Kampala, which is the capital city of Uganda, a low-income country. Data was collected using an interviewer administered questionnaire which was an adaptation of a validated tool adapted from a similar study conducted in Karachi, Pakistan ((1, 2)

Study setting

The cross-sectional survey was conducted in two urban markets of Nakawa and Wandegeya and shopping malls in an upmarket part of Kampala, Garden City mall. Nakawa is the largest government owned market, estimated as having space for 4000 vendors while Wandegeya market is the only government owned market in Kawempe division of Kampala city. Kawempe division has the highest population density in Kampala and therefore Wandegeya market is estimated to serve a high proportion of the urban population in Kampala. Both these markets provided a diverse sample population with adequate numbers from both vendors and shoppers. Garden city mall was selected because it is one of the most popular shopping areas for the population from a higher socio-economic status.

Sampling

A total of 395 community members from Kampala were sampled conveniently from Nakawa market, Wandegeya market, Acacia mall and Garden city mall. The participants consisted of market vendors and customers from the urban community who were shopping in these areas. The sample size was calculated using Kish and Leslie formula to give a power of 90%

Selection criteria

Inclusion criteria

All adults 18 years and above who consented to the study were interviewed.

Exclusion criteria

Adults who were unable to communicate in English or Luganda which are the common languages of communication among the urban population.

Data collection and analysis

Data was collected using a pre-tested questionnaire which was translated in English and Luganda. The questionnaire was administered by 2 trained research assistants. The data collected from the questionnaires was entered into a statistical program (SPSS or STATA) for analysis of the different variables. Descriptive analysis of the independent variables of sex, occupation, religious affiliation, education level of the community sampled and their knowledge about organ donation and transplantation was done. This was described as frequencies, means and averages and was represented

in tables, graphs, and pie charts. Bivariate and multivariate analyses were done to describe what effect the various independent variables have on the participants' knowledge about organ donation services. Attitudes were captured using questions with a 5 point Likert scale as well as open ended questions about the participants' opinions. Analysis of the responses was done using frequencies of responses for the Likert scale questions and a sentiment analysis using ATLAS word analysis for the open-ended questions.

Limitations

There were challenges with obtaining a quiet and private space to conduct the interviews in the markets and the shopping malls. This was mitigated by conducting the interviews in the office of the market managers. We did not capture information from the population which was unable to communicate in English or Luganda. However, this was the minority because most of the population was able to communicate using either of the 2 languages since Kampala is in the Buganda region where Luganda is widely spoken and used for day-to-day communication in the markets and the shopping mall.

RESULTS

In total 395 participants responded to the survey with a male: female ratio of 1:1 and highest level of education being Tertiary (29.11%) while 10.38% had no formal training whatsoever (Fig. 1).

Most of the respondents (79%) were Christian being either Catholic, Protestant, Pentecostal, or Seventh Day Adventist (Fig. 2).

Knowledge/awareness about organ donation and transplantation

Most of the respondents who participated in the survey had heard about Organ Donation in the last 12 months (66.58%) while 57.22% of respondents had heard about Organ transplantation in the last 12 months. The major source of information was Radio/ TV (46.05%) for organ transplantation and 45.04% for Organ donation. This was followed by social media (33.21%). Other sources of information combined contributed 21.75% (Fig. 3).

Knowledge on government policy/position on organ donation and transplantation

Only 6.84% of respondents were aware of a government policy in organ donation in Uganda while only 8.1% of respondents were aware of a government policy on organ transplantation in Uganda.

Knowledge of individuals who have donated their organs or received an organ.

Most of the respondents (76.71%) did not know of any person who had donated an organ. However about 1 in 4 of the respondents (23.29%) knew of a person who had donated an organ. A third of

respondents (33%) knew of a person who had received an organ. The commonest organ that respondents knew about being donated or transplanted was the kidney (75%) followed by the heart (14.7%) and the liver (4.65%) most of these operations being conducted outside Uganda.

Attitudes towards organ donation and transplantation.

A sentiment analysis on the attitude towards organ donation and transplantation was mostly positive (Fig. 4).

Positive sentiments for positively phrased questions were strong agreement or agreement, neutral for undecided, and negative for disagreement and strong disagreement based on the responses. Results of positively phrased questions are represented in the figure below (Fig. 5).

For negatively phrased questions, positive sentiments were for strong disagreement and disagreement, neutral for undecided, and negative for strong agreement and agreement as given on the Likert Scale.

Most of the respondents at all levels of education had a positive sentiment towards Organ donation (Table 1).

Table 1

A cross tabulation showing the distribution of sentiment on organ donation versus the different levels of education of the respondents.

	No formal Education (%)	Completed Primary (%)	Completed Secondary O-level (%)	Completed Secondary A-level (%)	Tertiary level (%)	Total
Negative	17 (10.18)	34 (26.98)	40 (25.00)	31 (24.22)	45 (20.09)	167 (23.82)
Neutral	6 (9.52)	15 (11.90)	28 (17.50)	28 (21.88)	65 (29.02)	142 (20.26)
Positive	40 (63.49)	77 (61.11)	92 (57.50)	69 (53.91)	114 (50.89)	392 (55.92)
Total	63 (100)	126 (100)	160 (100)	128 (100)	224 (100)	701 (100)

In the open-ended questions about organ donation and transplantation 280 participants (70.89%) gave responses. The most expressed positive sentiment using the word cloud analysis was the need for Sensitization of the community about organ donation (Fig. 6).

Other sentiments that were expressed were government facilitation, government implementation, training, and voluntariness in organ donation as shown in Table 2.

Table 2

Examples of positive sentiments expressed about organ donation and transplantation

Sentiment Type	Open-ended key word/phrase (%age of responses)	Examples of the Open-ended Statement about Organ Donation
Positive Sentiment	Sensitization (26.58%)	Ugandans need more sensitization on Organ Transplant. Educate people about Organ Donation Educate the Public more
Positive Sentiment	Government Facilitation (4.56%)	The government should open up several facilities especially in the village so that people can donate. These facilities should be spread across the country. Government should empower ministry of health with more equipment Government should import all machines to save our lives in this country
Positive Sentiment	Voluntary (4.45%)	Let Donation be optional and not by force Donation should be done freely without payment It should be by someone's free will
Positive Sentiment	Facilitation (4.30%)	The Government should equip all its health facilities Construction of more hospitals To put enough hospitals for Organ Donation
Positive Sentiment	Government Implementation (3.54%)	The Government Should but the exercise in motion The donation program is very important, and government should commit to implement it The government should put the exercise in action
Positive Sentiment	Compensation (2.78%)	Donors should be support/Compensated so that they can recover There should be compensation The Government should compensate those who are donating their organs

Sentiment Type	Open-ended key word/phrase (%age of responses)	Examples of the Open-ended Statement about Organ Donation
Positive Sentiment	Hospitals (2.78%)	<p>Construction of More Hospitals</p> <p>Government should construct health facilities first and educate health workers.</p> <p>The government should equip hospitals with Organs of the deceased.</p>
Positive Sentiment	Training (2.78%)	<p>The Government should put education sites about Organ Donation.</p> <p>The Government should educate about organ donation</p> <p>Efforts in education sector to educate more professionals who will operate and run the health facilities</p>
Positive Sentiment	Research Implementation (2.53%)	<p>Government should invest in Research activities and make sure they are implemented.</p> <p>Take this research seriously and implement what has been decided</p> <p>Government should invest in research and make sure they are implemented</p>
Positive Sentiment	Government Funding (2.28%)	<p>They Should Allocate funds to support Organ Donation Program in the country</p> <p>The government should ensure the hospitals have enough equipment to avoid loss of lives due to lack of fund</p>
Positive Sentiment	Doctors (1.52%)	<p>Government should help out more through Training, Educating Doctors, and constructing health facilities.</p> <p>Ask the government to train doctors and have drugs so that poor people can freely donate without fear.</p>

The most commonly expressed negative sentiment about organ donation using the word cloud analysis was fear followed by stricter laws and dangerous/high risk (Table 3).

Table 3

Responses expressing negative sentiments about organ donation and transplantation.

Open-ended key word/phrase(% responses)	Example of Open-ended Statement.
Fear (1.27%)	Fear of what comes next after donation.
Stricter Laws (0.76%)	There should be stricter laws because there would occur killings of people and comen prefer to get money
Dangerous/High Risk (0.76%)	It is very dangerous
Unsure (0.51%)	We don't know how safe it is
Cheating/Corruption (0.51%)	The government is too corrupt

DISCUSSION

Organ transplantation in low-income countries is relatively underdeveloped, despite the fact that the first transplant was performed in 1936 (3). Africa as a whole has been slow to develop organ donation programs compared to South Africa and some Northern African countries, which have made significant progress in establishing such programs (4–6). Several factors may contribute to the delayed implementation of organ donor programs in low-income countries, including the high cost of running these programs (7, 8).

Organ donation and transplantation process

Organ donation and transplant practice in Africa is generally limited to sibling and close relative donors, as there are few screening for other living donor programs in place. While some countries in Africa have made progress in establishing organ transplantation programs, many are still lagging behind. In some cases, the lack of resources and funding has made it difficult to implement effective screening programs and infrastructure to support organ donation and transplantation. As a result, sibling donors and close relatives often provide the only viable option for patients in need of an organ transplant. Despite these challenges, there is ongoing work to improve organ donation and transplantation practices across Africa, with a focus on expanding screening programs, increasing access to donor organs and legal regulation of organ donation and transplantation services.

Knowledge about organ donation and transplantation

The attitudes of individuals towards organ donation are influenced by a complex interplay of societal norms, beliefs, and existing legislation. Knowledge about organ donation and transplantation is a crucial factor in the successful implementation of organ donation and transplant services. However, there is a general lack of knowledge about these services, which can impact the uptake and utilization of organ donor programs. This, in turn, can lead to a shortage of donors despite the high demand for these

services. Knowledge in the general population is also greatly limited in different countries and this is partly due to the limited amount of knowledge dissemination to the population about organ donation (9). In different studies, over 60% of the population has very limited knowledge on organ donation in Africa (10). The lack of knowledge among populations greatly affects the need and acceptance of the program (11).

However, in this study there was an overall high knowledge about organ donation and transplantation among the urban population which may be a positive indicator to introduction of these services in the urban population.

Among medical workers and medical students, there was great variability in the lack of knowledge in different countries in (12, 13) This greatly limits the availability of organ transplant services among the population. This may greatly reduce the likelihood of a medical care provider recommending an organ transplant to a person who needs it. Although this study did not assess knowledge and attitudes among the health care workers, it was interesting to note that few participants got to know about organ donation and transplantation from health facilities. It might show that healthcare workers did not mention these services since they did not know about these services or their availability in their units. Among key decision makers and policy makers, knowledge about organ donation is critical as they play a critical role in the implementation of such programs (14). Further study about knowledge among these stakeholders is crucial in determining a successful implementation of organ donation and transplantation services.

Factors affecting attitudes towards organ donation.

Various factors determine the attitudes toward organ donation even when knowledge is available. Religious influence has been recognized to affect treatment practices among some faiths including affecting transfusion practices among others treatments (15). These attitudes may therefore directly affect the acceptance of organ donation in a population. It was observed that religious leaders played a big role in influencing the perception of their flock towards organ donation (16). Participants in this study were mainly from the Christian religious denominations and Muslim. It would be important to understand if religion and spiritual beliefs have an influence on the attitudes of an urban population towards organ donation and transplantation. Our study did not specifically look at the effect of religion although there was a high knowledge about organ donation regardless of the religious denomination one ascribed to.

The level of education affects attitudes to organ donation and transplantation. It is generally understood that the educated population groups are more likely to participate in organ donation (17, 18). In this study most of the participants had a primary level of education and above which could have contributed to their positive attitude towards organ donation and transplantation.

Societal norms and culture also play a role in attitudes towards organ donation and transplantation, and these can present ethical dilemmas at a personal level and community level(19). Understanding the societal and cultural attitudes are essential in increasing acceptance of the program in Uganda and sub-Saharan Africa. Several studies in Europe, Asia and America, and across various religious denominations

have shown that religious beliefs have an influence on organ donation practices (15, 16). The urban population in this study had various religious affiliations and the religious leaders could therefore serve as a source of information and spiritual and moral guidance for organ donors and recipients. Further studies could help to better determine how the various religions affect organ donation and transplantation practices in this population.

Information about organ donation and transplantation was obtained through radio/TV and social media. This shows that sensitization of the public about these services will best be done through these avenues. However, health care providers also need to know that these services are available and provide information to patients and the general public through radio/TV and social media.

Regulation of organ transplantation

In the developed world consent for organ donation can be written or oral and may be given by the deceased before his/her death or by a third party, usually a close relative or friend. In the UK, there is no requirement that the 'appropriate consent' for removal of organs and their use for transplantation be in writing provided it has been made explicit in some way (20). In India legal acts like the Transplantation of Human Organ Act try to address the widening gap and increasing demand for organs and the ethical challenges of transplantation tourism and organ trade in a low income population by looking into increasing the deceased donors aspect of organ donation (21). Key issues in successful development of organ donation and transplantation program are involvement of medical staff with specific professional training, promoting interpersonal communication among community members and campaigns aiming to create a more accurate perception of the entire legal and ethical framework surrounding organ donation and transplantation process (19). A World Health Organization survey of 47 countries in Africa showed that in most countries legal frameworks were inadequate and that regulatory frameworks for Organ donation and transplantation were weak and therefore unable to ensure effective regulatory oversight essential for implementation of quality standards for organ transplantation (22). The Uganda Human Organ Donation and Tissue Transplant bill by the time of this study was to be presented in the Uganda Parliament for approval. Most of the participants in our study were not aware of any regulatory body or laws that were governing organ donation and transplantation services in Uganda. The need for regulation and oversight of these services was expressed in the sentiments about stricter laws required to prevent killings for organs and for those profiteering from organ trade.

Limitations

We had challenges with obtaining a quiet and private space to conduct the interviews in the markets and the shopping mall. We offset these by conducting interviews in the market manager's office in the market.

We were not able to capture information from the population which was unable to communicate in English or Luganda though these were the minority. This was because most of the population was able to communicate using either of the 2 languages since Kampala is in the Buganda region where Luganda is

widely spoken and used for day-to-day communication in the markets and the shopping mall by the population who are not from Buganda.

Conclusions

Overall, there is adequate knowledge about organ donation and transplantation in the urban population of this low-income country. Sensitization of the community is required about government policy on organ donation and transplantation and this should be communicated through radio/television and social media. There was a positive attitude towards organ donation and transplantation. Negative attitudes towards organ donation and transplantation need to be addressed using the above-mentioned modes of communication. Regulatory oversight of organ donation and transplantation is necessary to promote trust and positive attitudes towards organ donation and transplantation.

Declarations

Ethics approval and consent to participate

This study was conducted according to the Declaration of Helsinki on conducting research with human participants. Ethical approval was obtained from the Makerere University College of Health Sciences School of Medicine Research and Ethics Committee and the Uganda National Council of Science and Technology. Administrative clearance was obtained from Kampala Capital City Authority and the local council or local community leaders of the selected markets and shopping mall to conduct the study in the shopping mall and the markets. Written informed consent was obtained from all study participants. The questionnaire was administered by a research team member in a private place at the recruitment sites for the community. The information obtained was de-identified to maintain confidentiality for the participants. Signed consent forms were stored in a secure cabinet in the office of the research study in Mulago for up to three years after the completion of the study. Participants kept a copy of their signed consent form and were reimbursed for their time.

Consent for publication

Not applicable

Availability of data and materials

The datasets analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Authors contribution

OK designed the study, collected data, analyzed the data and wrote the manuscript.

RM designed the study and edited the manuscript.

MO designed the study, collected data and reviewed the manuscript.

TM designed the study, collected data and reviewed the manuscript.

CI designed the study and reviewed the manuscript.

MW designed the study and reviewed the manuscript.

All authors reviewed the final manuscript.

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Figures

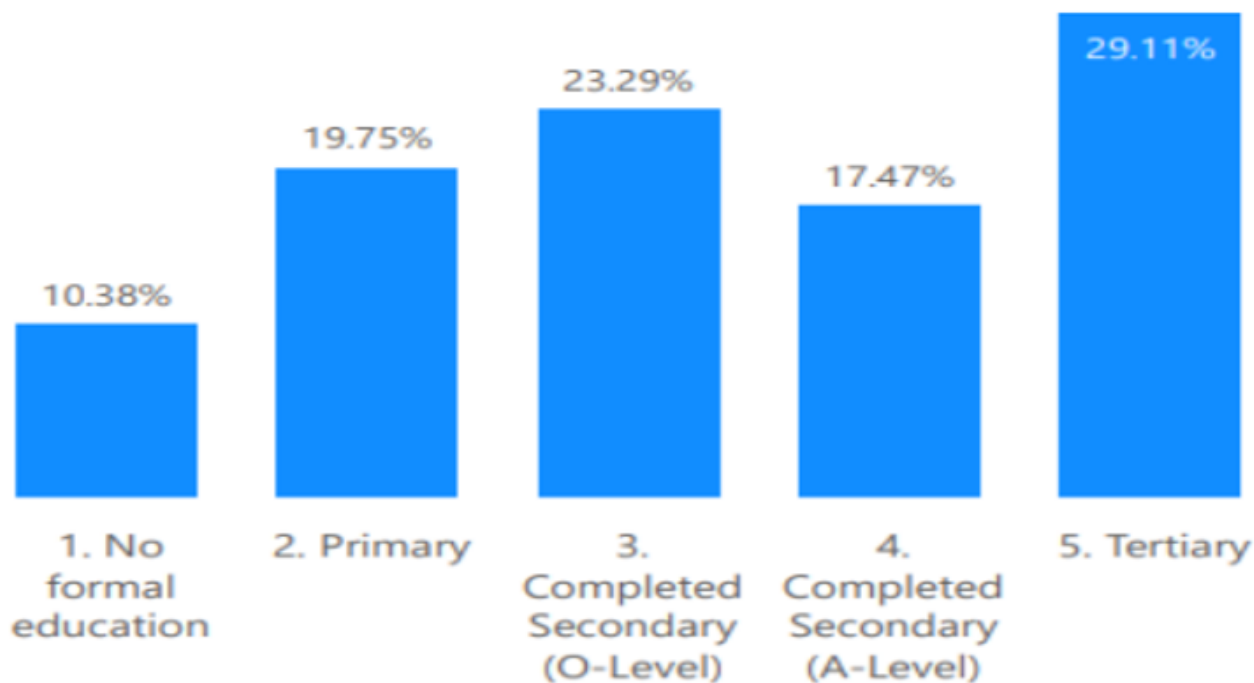


Figure 1

A column chart showing the distribution of respondents by highest level of education.

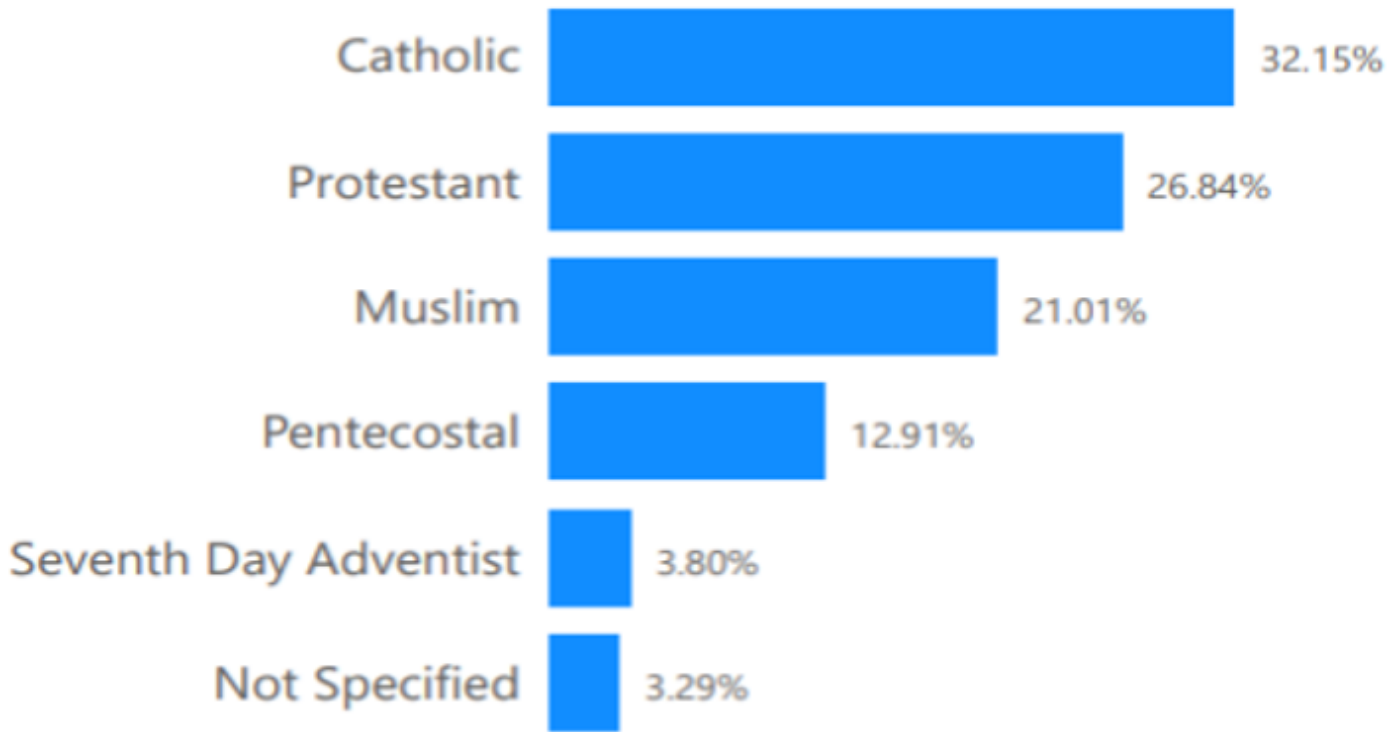


Figure 2

Religious affiliation of the participants

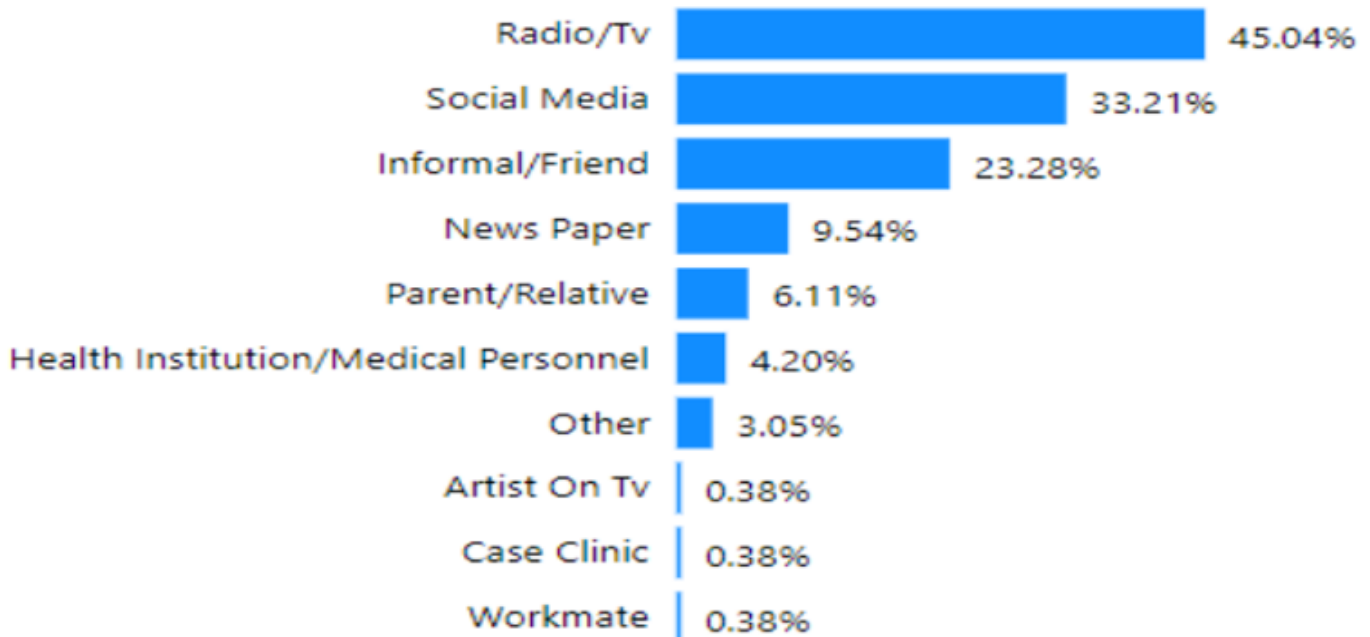


Figure 3

Sources of information about organ donation

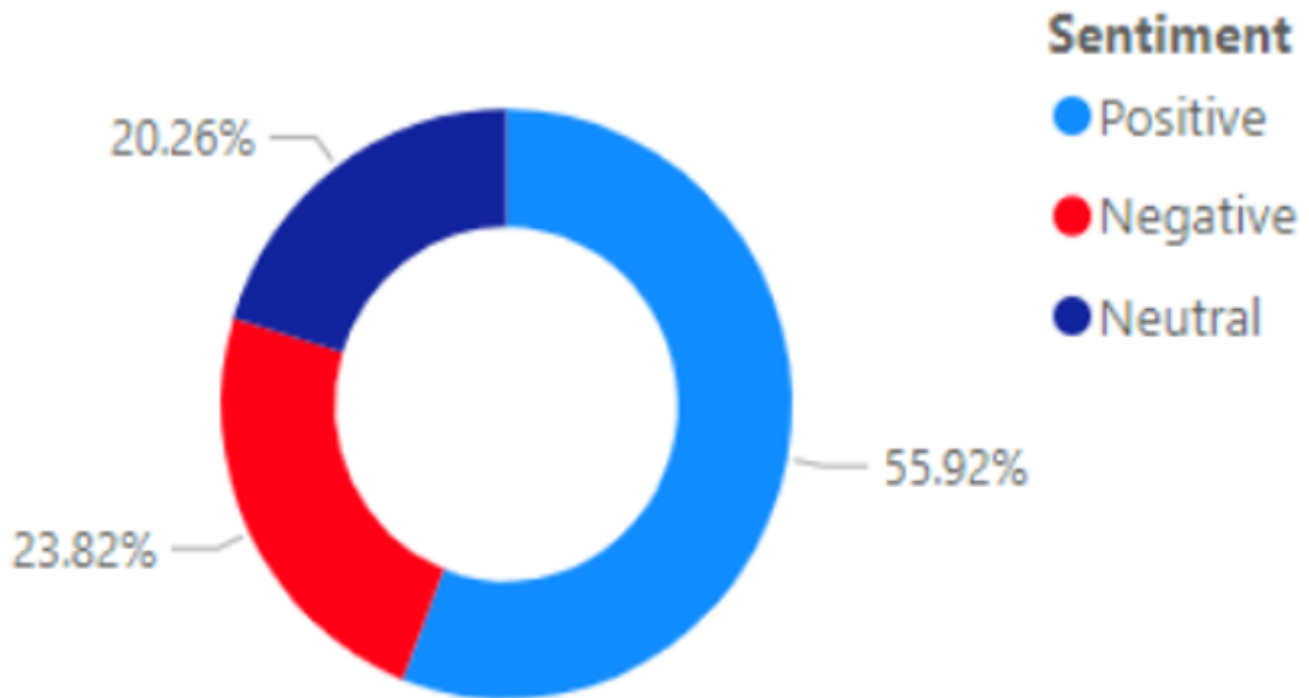


Figure 4

Distribution of participants' sentiments about organ donation and transplantation

