Perceptions and Barriers to Deceased Organ Donation in Armenia: A Qualitative Research

Nare Ghazaryan[1], Miqayel Adamyan[2], Samvel Grigoryan[3], Tatevik Hovakimyan[4]

[1]MD, Researcher, Nork-Marash Medical Center, Armenia, Yerevan
[2]MD, Researcher, Tutor, Head of Nork-Marash Medical Center, Armenia, Yerevan
[3]Reseracher, American University of Armenia, School of Public Health
[4]MD, MPH, MSc, Nork-Marash Medical Center, Armenia, Yerevan

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Abstract

Background and aim: Transplantation is the treatment of choice for end-stage organ failure. The worldwide shortage of organs focuses the attention of scientific community and policymakers on it. Despite having a favourable legislative framework Armenia still do not perform transplantation from deceased donors. Aim of this study is to understand perceptions and barriers of deceased organ donation in Armenia.

Methods: This qualitative study utilizes semi-structured, in-depth interviews to produce rich descriptions of healthy adult individuals and main stakeholders about the perceived drivers and barriers to deceased organ donation and transplantation in Armenia. Participants included healthcare providers, policymaker, priest and healthy adult individuals of other occupation. Content analysis with deductive approach was utilized.

Results: 11 in-depth interviews were performed. The main concepts around which the themes evolved were knowledge, attitudes, interaction with health system, family, cultural, religious and socioeconomic factors. Several factors emerged during the interviews: lack of knowledge, medical distrust, role of the donor's family as a buffer and misinterpretation of religious stance are examples.

Conclusion: Lack of knowledge regarding the brain death and deep mistrust to healthcare system were identified as the major barriers to acceptance of donation after death. It is recommended to conduct a comprehensive educational and awareness raising campaign both for public and providers.

Keywords: Organ transplantation. Brain death. Medical mistrust

Introduction

First successful kidney transplantation was performed in 1954 in Boston [1]. The barrier of genetic compatibility fell after introduction of immunosuppression [1]. Success of immunosuppressive therapies resulted in significant increase in the number of transplanted solid organs [2].

Armenia is a lower-middle income country in Caucasus, between Iran, Georgia, Turkey and Azerbaijan. It is highly monoethnic country (98.1% are Armenians according to 2011 census) with more than 94% being Christian. Armenia's transplantation law was enacted in 2002.

Presumed consent is the legislative default for deceased organ donation in the country. Armenia's overall transplantation rate of solid organs is 3.79 per million. Before 2019 only kidneys from living donors were transplanted. In 2019, the first two adult

Corresponding author:
Nare Ghazaryan MD
Researcher, Nork-Marash Medical Center, Armenia, Yerevan
Armenak Armenakyan St. 13, 0047 Yerevan, Armenia
Email: nareh.ghazaryan777@gmail.com
Tel.: 00374-94-92-42-49

and pediatric liver transplantations were performed from living donors [3]. No deceased organ donations have been performed in Armenia till now. The need for organs is significant given the high prevalence of end-stage organ diseases in the country.

It is imperative to understand community perceptions to organ donation and transplantation in the country and suggest policy implications for further improvement.

Methods

This qualitative study produces rich descriptions of healthy adult individuals and key informants about perceived barriers and drivers to deceased organ donation and transplantation in Armenia.

The study conceptual framework was adopted and slightly modified from the Irving's 2009 study. It demonstrates the balance of attitudes to deceased organ donation and transplantation process in the form of a scale, which is balancing the drivers and barriers between main concepts regarding the topic [4]. Concepts were knowledge, attitudes, interaction with health system, body integrity, family/relational ties, cultural aspects, religious beliefs and socioeconomic factors.

Semi-structured in-depth interviews were conducted among healthy adult individuals and key informants. They allowed to understand deep feelings, knowledge and attitudes of all groups.

The data were collected using individual, semi-structured in-depth interviews with study participants. Demographic parameters as age, gender and occupation were also collected.

The semi-structured interview guide consisted of 10 open-ended questions, which were administered to participants after obtaining a preliminary written consent. The questions were constantly discussed until repetition was observed. Almost all interviews were recorded with permission of participants. Interviews were continued until the data reached saturation. At the end of the interview, all the participants were asked for specific recommendations to improve the situation. The study interview guide was adopted and modified/ suited for Armenian participants from a South Korean study [5].

A purposive sampling method was the method of choice to reach interviewees. All study participants were recruited using individual connections of primary author. The study population consisted of the following groups:

- Healthy adult individuals – these were young people aged from 25-40,
- Healthcare providers with potential to be involved with the process of donation and transplantation- cardiovascular surgeon, renal transplant surgeon, liver transplant surgeon, intensivist.
- Former Minister of Health of the Republic of Armenia,
- Psychiatrist,
- Priest.

All the interviews were recorded with permission of participants. One of participants refused the recording, so the primary investigator took the permission to take notes on her answers. The recordings were transcribed verbatim in Armenian the same day. The participation in the study was anonymous for ethical reasons, so each participant was given an ID in the process of transcription. Audio recordings were performed using an iOS device with a fully encrypted hard drive and transcribed the same day. No personal details were collected as name, workplace, phone numbers or addresses. Only the author had access to data and performed the process of audio recording and transcription herself to avoid dissemination of sensitive material.

Demographic data were analysed with help of Microsoft Excel Spreadsheet. A conventional theory-driven content analysis with deductive approach has been applied to analyse the transcribed data [6]. Data obtained were coded using meaningful words, phrases and sentences, which combined into major themes and categories [7]. The process of analysis was done manually in original Armenian language to avoid any changes in content and meaning of the phrases and misinterpretation of information [8]. The pre-determined themes were taken from the literature. The main themes around which the coding of data was performed were: 1) Religious; 2) Cultural; 3) Family; 4) Body Integrity; 5) Interaction with health system; 6) Knowledge; 7) Socioeconomic; 8) Attitudes. The choice of deductive approach is justified by the fact, that there is a significant amount of qualitative research focused on the topic of organ donation and transplantation. Triangulation of data analysis results between healthy individuals, healthcare providers

and policymaker significantly increases the credibility of the study results [9]. In addition, to strengthen the trustworthiness of the study, participant validation method (member check on spot) was used: the interviewer rephrased the information received from participant and returned to them to be sure that they reflected the meanings of their ideas clearly [10].

Results

Overall, 10 in-depth interviews were conducted with 11 separate participants. The mean age of participants was 47y, ranging from 25 to 72. Eight of them were male participants. Mean duration of in-depth interviews was 18 min, ranging from 7 to 37min. All the responders had a graduate degree of education.

There were eight predefined themes chosen for the study.

1. Knowledge

Knowledge about brain death

All the non-healthcare professional respondents did not know the definition of brain death. It was commonly misinterpreted as inability to think or absence of consciousness, a vegetative state, when all other organs work properly and brain does not. They also had psychological difficulty to interpret brain death as death of whole organism. Healthcare providers and policymaker had different opinions – those, who were involved in living organ donation and transplantation processes formerly, had proper understanding of what is brain death and its irreversible nature. Those who were not involved in the process of organ donation and transplantation, could also misinterpret it as a "vegetative" state, without knowing the exact diagnostic methods of irreversible brain death.

"Brain death is, when the brain stops, does not think. I don't know if other organs can work. It's really interesting, isn't it?" (sports NGO worker, 27)

Understanding the need

Majority of respondents agreed on the fact that the demand of organs for transplantation is crucial and that it is not possible to close the gap with only living organ donations.

"I know a person, who escaped to Belgium for getting a liver transplant, lived in a ghetto for months and eventually became sick with AIDS, which made everything meaningless. It would be better, if we could organize this using our own resources and would not leave people helpless or force them to leave the country." (Psychiatrist, 40)

2. Attitudes

Overall attitude to organ donation was very positive. All the respondents agreed with the fact that if the brain is dead, there is no need to keep the remaining organs. There were minor precautions again about validity of brain death. One of the respondents (non-healthcare provider) had philosophical concerns about increasing number of people living on earth. The other concern raised was the potential for commercialization.

"I have a very positive opinion about organ donation and transplantation. For me it is a very healthy and humanistic attitude. The only concern is declaration of death after brain death". (journalist, 40)

3. Interaction with health system

Medical mistrust

The answers concerning the mistrust to doctors and overall healthcare system were highly repetitive, this was the most frequently mentioned barrier perceived by all participants. The culture of mistrust seemed to be enrooted deeply in the relationship of patients and providers. It related to different aspects of donation and transplantation processes: people did not trust the system's capability to perform it with normal quality, availability of infrastructure was of concern, fear of organ trafficking and development of black market, validity of brain death and possibility of intentional and unintentional euthanasia were major concerns. At the same time, they also recognized that this issue of trust and mistrust is something irrational, which could require major reforms in the system or only a role model (like a good, competent minister of health), who could lead the change management process. There were also answers from health providers, stating that the medicine in our country is pretty developed and physicians' potential is not of concern.

"You know, the question is comprehensive: we need an exclusive trust in physicians, that they did everything to save the patient's life, but failed" (renal transplant surgeon, 69)

4. Body integrity

Thoughts about distortion of body integrity did not come out frequently. Only two of respondents had that concern, not for themselves, but for others. General opinion was that it is not a major problem.

"Maybe they [the relatives] think, that it is better to decay under the ground, than to be helpful to someone? I know that frequently people give money to "correct" the face [of the deceased] before burial. We have such stupid things" (Food manager, 29)

5. Family/relational ties

All respondents agreed that the family of the donor plays a crucial role in our society and it is imperative to take their permission before proceeding with organ procurement. Majority of healthcare providers agreed that with proper and timely preparedness (i.e. that the family knows the wishes of the deceased person well ahead of the tragic event) and adequate trust to health providers they would agree to donate the organs.

"Many things depend on the impression of family: If they feel that everything is done for their patient, he was treated conscientiously, they will not be against" (Intensivist, 63)

6. Cultural

Majority of respondents agreed on the fact that we need to develop as a society to understand not only the importance of our personal ego, but to look at facts as a society, as a whole. Lack of teamworking ability and residential perspective were frequently mentioned as barriers which was explained by the fact that if people need to think about day-to-day survival, there is no time to consider donation and help to society, which is a remote and less tangible target. The other cultural barrier noted was the importance of opinion of neighborhood, which frequently could be negative toward donation and transplantation.

"Opinion of the neighbors is very important. One of the recipients telling that the villagers constantly blamed her for taking the organ of her daughter" (Liver transplant surgeon, 50)

7. Religious beliefs

Common opinion was that the role of the church will be tremendous to foster or prevent the process of organ donation. Some of the respondents who were standing closer to church favored the idea of altruistic donation or giving to their neighbor, their proponents argued that the official apostolic church will be against the organ donation because the body should keep its wholeness to be ready for the second advent of Christ: this view was not shared by the priest-interviewee.

"If it is possible to save one's life with donation, then why not doing it? I think of it as a manifestation of Christian compassion and sacrifice" (Priest, 53)

8. Socioeconomic factors

Among frequently mentioned factors were adequate financial compensation to providers and need for financial resources to accomplish the establishment of service. It was mentioned that high-income people would be more prone to discuss the donation of their organs after death. Improvement of education system and advocacy of humanitarian principles were other drivers of the process.

"Those are hard questions, we know definitely, that everything to be done should be compensated properly" (former minister of health, 72)

Discussion

Our study results demonstrated that there are several barriers to development of system for deceased organ donation and transplantation in Armenia. Among them, the deep mistrust to the health system and providers was the most prominent. It was mainly explained with the previous distrustful experience with the system and questioning the doctors' ability to diagnose the brain death adequately.

In our study we did not observed concerns regarding treating the body of the donor with respect and dignity, or using the organs for experiments [11], but there were major concerns about unequal distribution or even "sales" of donated organs.

The best solution in this situation would be "to make donation happen for those who want it", or at least we believe, that they do. The respect for person is the legal and ethical basis of basic law almost everywhere, including in Armenia.

Another barrier which was frequently mentioned was the lack of knowledge about the "dead donor rule" and its frequent misinterpretation. Even some healthcare providers could not differentiate between the end-stage coma and brain death.

The good news is that majority recognize the need for establishing the system for deceased

organ donation and transplantation and with good educational effort it would be possible to improve the situation [12] [13].

General attitude to organ donation and transplantation idea was really favourable in our research, everyone agreed that it is humanistic and kind, the best motivator being the human altruism as mentioned elsewhere in the literature [14].

Role of the donor's family as a surrogate decision maker was perceived as highly important in our study, which could affect the donation rates in both positive and negative meanings.

Armenian Apostolic Church views do not reject the idea of organ donation, but is overall favour of it, provided that everything was done to save the life of the donor.

Based on our findings, several recommendations can be made:

1. As a first step it is recommended to conduct a comprehensive quantitative research with a country-representative sample to understand the acceptance rates for deceased organ donation in Armenia;
2. Comprehensive program educating and raising awareness of general public about the need of organ donation, including social advertising with help of well-known actors and role models;
3. Special education and training of healthcare providers who will be involved in transplant services;
4. Inclusion of all transplantation procedures in Basic Benefit Package offered for people with disabilities;
5. Adequate compensation mechanisms for specialists to avoid the presence of informal payment to providers;
6. Finally, governmental support and leadership are imperative for developing this initiative and build the necessary trust to it.

Limitations and strengths

The major limitation of our research is its external generalizability, as a major limitation of all qualitative studies. Our intention was to understand the deep feelings, values and attitudes towards organ donation in Armenia. To our best knowledge, this is the first study exploring the perceptions and barriers of deceased organ donation and transplantation in Armenia. Its findings point out on the potential facilitators and barriers for establishing the service in our country.

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