Attitudes and perceptions among Iraqi young adults towards organs donation and transplantation: A call for action

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Abstract

Background: Organs transplantation is the only treatment for end-stage organ failure. However, the disparity between organs availability and the number of patients in the waiting lists is widening globally, especially in Iraq for many reasons. This study aims to assess the level of attitudes and perceptions among Iraqi young adults towards organs donation and transplantation as the first study to be conducted in Iraq for such purpose.

Methods: This observational study was conducted among 912 Iraqi young adults through a structured questionnaire which was disseminated among social media platforms. Participants consented before filling the questionnaire and their responses were analyzed to test the hypothesis of the study.

Results: Most of the participants were females, Muslims and in their undergraduate level. Overall, 84.2% of the participants were willing to donate their organs after death and (97.9%) of them actually agreed to sign for organs donation. Most of those who were not willing to donate have no idea whether their religion approves it or not. There was no statistically significant difference in willingness to donate between different socioeconomic classes or residency areas.

Conclusions: Most of the participants are convinced with donating their organs after death and are willing to sign for organ donation programs, advocating for initiating an official governmental transplant agency with multiple local committees distributed among health directorates all over the country managing it. The hesitancy to donate organs was attributed mostly to religious and associated with lack of knowledge issues, thus education might be the key to positive attitudes.

Introduction

End-stage organ failure meant inevitable long suffer and probably death around 50 years ago. However, surgical techniques, immunological and molecular biology advances have made organs donation and transplantation the life-saving solution from the immense death.1

Still, the need for transplantation is emerging day by day, and the gap between organs available for transplantation and the number of patients in the waiting lists is widening globally.2 In Iraq, the program for kidney transplantation was launched in the early 1970’s. Legislation which permitted organs donation from living and deceased-donor was approved for the first time in 1985. Nevertheless, this concept did not gain popularity. The first transplants were performed using living related donors exclusively. Now, seven living-donor renal transplantation programs are functioning with the availability of 5 HLA and tissue typing with no deceased-donor transplantation program.3,4

Iraq’s population is around 38,872,655 according to the latest study (July 2020) by the Central Intelligence Agency.5 Among those, 50.2% are males and 49.8% are females forming a sex ratio of 1.01 which is lower than global sex ratio. More than 70% of the population lives in an urban environment around the major big cities, the rest are located in more rural areas around the country. Elderly (ages more than 60) in Iraq form around 5%. The youth (ages 15-24) constitute 19.24% of the total population. Legislation which permitted organs donation and transplantation for the first time in 1985. Nevertheless, this concept did not gain popularity. The first transplants were performed using living related donors exclusively. Now, seven living-donor renal transplantation programs are functioning with the availability of 5 HLA and tissue typing with no deceased-donor transplantation program.3,4

The unemployment rate among the youth is 25.6%, more among females (63.3%). Poverty in Iraq is high, with 23% of the total population spending less than $2.2/person/day.5,6

As for most of the world’s countries, Iraq is a mixture of different religions in which Muslims form 95-98% of the population, Christians 1% and other religions forms 1-4%.6

All over the time Islamic scholars, authorities and institutions clearly stated religious acceptance of both living-donor and deceased-donor models. Accordingly, Muslims show agreement to the idea despite some theological uncertainty on the legality of only brain-death criterion in the context of deceased-organ donation.7

The level of awareness towards organs donation and transplantation in a population reflects its attitudes towards such concept. The research into this field is unsatisfactory in Iraq unfortunately. Databases search revealed no published articles assessing the concept of organs donation and transplantation among our population. This study aims to assess the level of attitudes and perceptions among Iraqi young adults towards organs donation and transplantation and their willingness to donate organs while high
lightening the main challenges preventing this concept from growing popular in order to cover the need for organs donation and transplantation, being the first study to be conducted in Iraq covering these medically and socially important concepts.

Methods

Study design

This observational study was conducted among 912 Iraqi young adults. Participants were selected using convenience sampling. Non-Iraqi participants, Iraqi participants older than 29 years and those who didn’t consent were excluded from the study. The overall response rate was 99.3%.

Study Questionnaire

A structured questionnaire was employed to evaluate the attitudes and perceptions among participants. The questionnaire composed of an introductory page (explanation about the study’s aim, role of participants and final consent) and 3 sections: demographic data, socioeconomic status, attitudes and perceptions on the concept of organs donation and transplantation. The latter covered the following concepts: subject’s awareness of organs donation and transplantation, related laws, willingness to donate organs after death and if otherwise, the reasons for not willing to do so. For the socioeconomic status, Modified Kuppuswamy scale (Table 1) was used and the participants were classified into three classes for the purpose of analysis according to their score and as follows:8

- Upper class (26-29)
- Middle class (11-25)
- Lower class (3-10)

Participants willingness to donate and willingness to sign for organs donation were assessed according to their responses. Only “Yes” and “No” responses were allowed in these questionnaire items.

The questionnaire was presented in Arabic language to suit the general public.

Data collection

Data was collected for 5 days (21st-25th of May 2020) through dissemination of a Google Form questionnaire. We sent the invitation link of the questionnaire with illustrative message about the study’s background and objectives in various Iraqi youth gathering groups, including various university students’ groups on Facebook, Instagram and Telegram which are the most popular social media platforms used by young adults in Iraq. We managed to consider the geographical distribution of the groups’ members to offer equal chances of participation all over Iraq. We asked all participants to further distribute the invitation link of the questionnaire among their family members, friends and neighbors.

Bias avoiding efforts

Participants filled the questionnaire by themselves where all the questions were posed neutrally, then their responses were translated back to English using predefined operational terms to establish the different groups of the study.

The questionnaire was e-mail-protected, and participants could fill the form only once with their logged in e-mail. Moreover, we didn’t mention the criteria of the required age for participation to minimize any inaccurate details inserted by participants just to be part of the study. However, we did personally exclude those who were not fit with the desired criteria before data analysis.

Ethical consideration

Participants consented in the first part of the questionnaire for using their responses in making the data of the study. They were not asked for their names, and all the responses were password-protected and only accessible to the investigators at the time of data analysis.

Statistical analysis

The collected data was analysed using Statistical Package for Social Sciences (SPSS) (version 25.0). Descriptive statistics were presented in frequencies and percentages using appropriate tables and figures for the purpose of comparison. For statistical analyses to compare the attitudes and perceptions across different categories of the study participants, χ²-test was performed to test the significance of each group. A p-value <0.05 was considered as statistically significant throughout the analysis. There were no missing values.

Results

Demographic data

Total number of people participated in the questionnaire was 944, after applying the previously mentioned inclusion and exclusion criteria 32 participants were excluded and the rest (912) were included in the study. The majority (72.7%) were females. All the participants were young adults (18-29 years old); 77.1% were residents of urban areas of their provinces, while 22.9% were residents of rural area. For the educational level, most of the participants (87.8%) are studying undergraduate degree at university or college while 3% are studying at postgraduate level. The minority responded as they are studying at high school level or primary

| Table 1. Modified Kuppuswamy scale with currency exchange from Indian Rupee to Iraqi Dinar (IQD) according to the exchange rate in Google on the 19th of May 2020. |
| Education of the head of the family | Occupation of the head of the family | Total income of the family per month | Income | Score |
| Education of the head of the family | Score | Occupation of the head of the family | Score | More than or equal to 830k IQD | 12 |
| Professional degree | 7 | Professional | 10 | 415k-830k IQD | 10 |
| Graduate or postgraduate | 6 | Semi-professional | 6 | 311k-415k IQD | 6 |
| Post high school diploma | 5 | Shop owner/ Farmer | 5 | 207k-311k IQD | 4 |
| High school certificate | 4 | Skilled worker | 4 | Less than or equal to 207k IQD | 1 |
| Middle school certificate | 3 | Semi-skilled worker | 3 | More than or equal to 125k IQD | 3 |
| Primary school certificate | 2 | Unskilled worker | 2 | 42k-125k IQD | 2 |
| Illiterate | 1 | Unemployed | 1 | Less than or equal to 42k IQD | 1 |
level (3.6%). The rest (5.9%) declared they are not studying at time of filling the questionnaire in which most of them (79.7%) had already finished their undergraduate.

Regarding the religious belief of participants, most of them (95.9%) were Muslims. For the socioeconomic status, 71% of the participants were in the middle class. The rest were distributed in the upper and lower classes (24%, 5%), respectively.

Attitudes and perceptions towards organs donation

From the 912 participants in this study, 768 (84.2%) are willing to donate their organs after death, and 704 (77.2%) actually agreed on signing for organs donation, if an official agency is to be established for this purpose in Iraq (Figure 1).

Among those who are not willing to donate their organs after death, 16.7% declared that their religious belief is prohibiting them from organs donation, while 26.4% declared no religious prohibition. On the other hand, the majority (51.7%) of those who are willing to donate their organs after death said that their religion is not prohibiting them from organs donation (Figure 2).

704 (77.2%) of the participants knew that donation is associated with health risks for the donor, and 733 (80.4%) knew about the health risks associated with receiving an organ (Table 2).

Overall, 770 (84.5%) participants believed that, one can donate more than two different organs after death, while 96 (10.5%) of the participants claimed that, it is possible to donate both the liver and kidneys after death. 46 (5%) participants thought that organs donation is limited to kidneys only.

Attitudes and perceptions towards organs transplantation

Overall, (79.6%) of the participants believed that donation can be done to anyone in need rather than exclusively to the next of kin as in (6.9%) of the participants. The rest (13.5%) had no idea pertaining to whom they can donate.

Regarding when someone can donate any organ, the majority (81.4%) knew that they can donate whether they are alive or deceased, while (11.3%) thought that donation can only be done when the donor is deceased, and the rest (7.3%) thought that the donor has to be alive in order to donate any organ.

More than half of the participants (56.9%) believed that the donor can, in fact, accept money as an exchange for donation, while only (4.5%) knew about the law in the Iraqi constitution that prohibit trading in organs and accepting money in exchange for donation (Table 2).

Table 2. Participants’ responses to certain questionnaire items.

| Questionnaire Item                                                                 | Yes (%) | Responses No (%) | Don’t Know (%) |
|--------------------------------------------------------------------------------|---------|------------------|----------------|
| Attitudes and perceptions towards organs donation                                |         |                  |                |
| Are there health risks associated with organs donation?                          | 704 (77.2) | 85 (9.3)         | 123 (13.5)     |
| Are there health risks associated with receiving organs?                         | 733 (80.4) | 68 (7.5)         | 111 (12.2)     |
| Do you think human organs black market is common in Iraq?                        | 323 (35.4) | 155 (17)         | 434 (47.6)     |
| Attitudes and perceptions towards organs transplantation                         |         |                  |                |
| Can someone accept money in exchange for organs donation?                        | 519 (56.9) | 253 (27.7)       | 140 (15.4)     |
| Is there an official law regarding accepting money in exchange for organs donation? | 41 (4.5)  | 368 (40.4)       | 503 (55.2)     |

Statistical analysis

There was a statistically significant difference between males and females in terms of willingness to donate organs (p=0.01) with the females being more willing to donate organs (86.1%) than males (79.1%) (Table 3).
There was a statistically significant association between willingness to donate and willingness to sign for organs donation if an official agency is to be established for this purpose (p<0.001) (Table 3). There was no statistically significant difference in willingness to donate among different socioeconomic classes (p=0.928) (Table 3). There was a statistically significant association between willingness to donate and whether the participant’s religious belief prohibits them from organs donation after death (p=0.001) (Figure 2).

Discussion

This study observed that the willingness to donate organs was different across genders with females being more willing to donate than males, this can be partly due to higher rates of end-stage renal disease among men; the United States Renal System reported that 57.2% of American people on hemodialysis in 2015 were men.9 Hodson10 in his article about gender kidney donation gap interprets this disparity using Carol Gilligan’s principal which argues that ethical decision making is different between men and women with women see the world bonding with each other through human connections rather than individuality. Men morality in decision making is characterized by justice and rights, on the other hand care, connection and interdependence tend to be more of women characteristics.10 And since organ donation is a critical moral decision, it, thus, falls under this hypothesis as well.

Medical anthropologists suggest a resonant analogy between giving birth and giving a kidney in their explanation of women contribution to organs donation. Mothers’ bodies were explicitly envisioned as the source of life from which both fully formed babies and organs could be extracted. Taking one more organ from that same source was rendered an organic continuation of that bodily intimacy and interdependence.11

Another factor contributing to this finding is that the notion of exposing the main breadwinner of the family to the consequences of organ donation may render the whole family in need. According to World Bank data based on modeled International Labor Organization (ILO) estimates,12 the ratio of female to male labor force participation rate in Iraq was 21.7% in 2017 (21.89 in 2016) making the man as the most probable individual to depend upon in the family. Thus, absence from work - due to surgery or complications of organ donation- will end up jeopardizing the whole family dynamics temporarily or, sometimes, permanently.

Socioeconomic status was not found to influence the willingness of organs donation among our study’s participants. This is in contrast to some studies published on other populations.13-15 This contradiction can be attributed to many facts. Firstly, several scales are available to filter the participants and assign them to socioeconomic classes. Lower socioeconomic class was occupied by 5% of our study participants. However, it was occupied by 37.19% in Mithra et al.2, in whose study a classification of only two extremes (upper and lower classes) was employed. Moreover, we managed to use multiple factors to assess socioeconomic status, thereafter we classified participants into upper, middle and lower classes to investigate statistical significance among participants fall in those classes (Modified Kuppuswamy scale). Similar factors were used by several studies.2,13,16 However, the way of using those factors to investigate the effect of socioeconomic level and willingness to donate organs was different. In Khan et al. a statistical significance was found as it investigated those factors one at a time rather than testing them all together in one individual by using a well-known local or international socioeconomic scale for proper judgment.16

The study has shown that more than 87.5% have finished high school and are studying in university or college at under- or postgraduate level. Previously published studies stated that educational level is significantly associated with willingness to donate organs.13,17 Thus, both the used socioeconomic scale and high educational level of the participants made socioeconomic status lack influence on willingness to donate organs.

The study has shown that around 84.2% of the participants are convinced and, in fact, willing to donate their organs after death. Similar studies were conducted on other populations to indicate their willingness to donate; for example, a study in Morocco by Flayou et al.18 showed that 65.7% of participants had a positive attitude towards organs donation. Other studies in Iran by Abbasi et al. and Saudi Arabia by Sayedalamin et al. showed that the percentages of young adults who had positive attitude towards organs donation were 49.69% and 41.2%, respectively.19,20

| Crosstabulation of participants in response to their willingness to donate organs among different questionnaire items. |
|---------------------------------------------------------------|
| **Sex** | **Willing to donate (%)** | **Not willing to donate (%)** |
| Male     | 197 (79.1) | 52 (20.9) |
| Female   | 571 (86.1) | 92 (13.9) |
| **Cross tabulation of willingness to donate and willingness to sign for organs donation if an official agency is to be established** |
| **Willingness to sign for organs donation** | **Willing to donate (%)** | **Not willing to donate (%)** |
| Yes      | 689 (97.9) | 15 (2.1) |
| No       | 79 (38)    | 129 (62)  |
| **Crosstabulation of SES and willingness to donate organs** |
| **SES Class** | **Willing to donate (%)** | **Not willing to donate (%)** |
| Upper    | 186 (84.9) | 33 (15.1) |
| Middle   | 544 (83.8) | 165 (16.2) |
| Lower    | 37 (86)    | 6 (14)    |

SES, socioeconomic status.
The reason why these studies were specifically chosen for comparison with our study is that they were done in countries that share the same cultural norms and religious backgrounds with Iraq. For example, 100% of the participants were Muslims in the studies conducted in Saudi Arabia and Iran.\textsuperscript{19,20} However, this study shows a strong positive difference in organs donation rate, which might be partly due to the fact that 72.7% of participants in this study were females, and since willingness to donate organs is higher among females than males, it is expected to gain a higher rate for willingness to donate organs than other studies with less female participation for example, female participation in Morocco was 48%.\textsuperscript{18}

Another reason explains this strong positive difference might be related to the knowledge about religion’s point of view regarding organs donation. In Sayedalamin \textit{et al.}, 91.3% of participants declared that their religion allows them to donate organs,\textsuperscript{20} on the other hand 38.3% of those who are willing to donate in this study (Figure 2) did not have an idea about their religion’s status of organ donation indicating that their willingness to donate is influenced by other factors that were not assessed in the study questionnaire.

In Sayedalamin \textit{et al.}, 41.2% of participants agreed to donate their organs to any deserving patient, however 50.9% were willing to donate their organs to their family alone.\textsuperscript{20} This disparity was also noticed by Abbasi \textit{et al.},\textsuperscript{19}, where 61.21% of participants were willing to donate their organs to parents or close relatives if they needed organs at particular situation. Thus, the prime motive to donate organs may in fact affect the overall donation rate in selected populations. Directed organ donation (donation to family, relatives and close friends) has higher rates than purely altruistic donation as shown in the above studies. In this study, the characteristics of the recipient were not assessed and those who are willing to donate their organs were not asked about their prime motive behind them agreeing to the concept of organs donation whether it is purely altruistic or directed to the next of kin. Many studies regarding rates of organs donation focus on the reasons behind rejecting organs donation in order to identify them and work on correcting the misunderstandings to increase the overall donation rate, but it should also be kept in mind for future research that reasons behind accepting organs donation also influence rate of organs donation itself as they might preclude some of those who already declared their willingness to donate their organs from donation if the characteristics of the recipients have changed.

This study provides sufficient evidence for the need for an active program to be up and running, in Iraq, handling the process of deceased-donation. Such initiative will help those who are willing to donate through inviting them for signing consents and getting a donor card (97.9% of those who are convinced with the concept of donation after death, committed to sign for an actual donation). Furthermore, it will help those who are confused with their decision through educating them about all aspects regarding the idea of organs donation (2.1% of those who are not convinced with that idea stated that they would consider signing in).

This study shows that 38% of participants are willing to donate organs yet they are reluctant to sign for organ donation (Table 3). Similar findings have been noted in other studies, for example in Sayedalamin \textit{et al.} 90% of participants supported organs donation yet only 5% had an organs donation card.\textsuperscript{20} Similarly, in the study by Cilloğu\textit{et al.} 44.4% of participants accepted organs donation yet only 10.3% were holders of organs donation card.\textsuperscript{21} The situation was far better in Symvoulakis \textit{et al.}, in which about 72% participants had a positive perception about organ donation, and 23% had organs donation card.\textsuperscript{22} This disparity between behavior and intention indicates that having positive attitudes do not necessarily map reliably onto actual commitment. In the context of organs donation, some people express willingness to be organs donors, yet do not obtain organ donor cards. The card here represents the actual commitment for organs donation, and it is important when it comes to the family members’ decision regarding organs donation who are more likely to consent when the deceased had signed organs donation card expressing his intention to donate organs after death.\textsuperscript{23} The incongruency between behavior and intention towards organs donation can be explained under the umbrella of Theory of Planned Behavior (TPB). TPB states that forming a behavioral intention requires three constructs: attitudes towards the behavior, subjective norm and perceived behavioral control.\textsuperscript{24-26} Given that the TPB explains less than half the variance on average in behavioral intentions, the extended form of TPB (which adds the moral norms, self-identity and in-group altruism to the constructs of TPB) is even more applicable for justifying the inconsistency between behavior and intention.\textsuperscript{27} Let’s take an example to simplify this concept; you are walking in the street with your friends and you see a homeless man begging for money, you want to give him money (you have the positive attitude towards giving him your money), but you are in doubt about what your friends are going to think of you (subjective norm), thus you preclude yourself from giving your money despite you had positive attitudes towards it in the first place. Absence of one of the constructs of the Theory of Planned Behavior can lead to reluctant interpretation of the desired behavior into actual commitment. For example, if the individual finds it difficult to talk the family into his will to donate organs after death, he will end up not donating organs despite having the intention to. Thus, intentional donation is different than the actual rate of donation and this fact is represented in this study with the 79 participants who are willing to donate their organs yet not willing to sign for organs donation.

Now how to influence the actual rate of donation and convince people to be commits to their initial will of donating organs is beyond the scope of this article, however different studies have proposed that working on the main constructs of TPB by using interventions of educational classes will increase the probability of people being committed to their desired behavior of organs donation.\textsuperscript{27,28}

Islam was the major religion among the participants in this study (95.9% were Muslims). This percentage is consistent with the fact that Islam is the most prevalent religion in Iraq which makes the sample closer to the population in terms of religious background.\textsuperscript{5} Out of 144 participants who were not willing to donate organs, the majority of them (56.9%) had no idea whether their religion agrees about organs donation or not, which explains their hesitancy towards organs donation. This is despite the Islamic theologians issued in 1986 what became known as the Amman Declaration, in which they clearly accepted brain death and the retrieval and transplantation of organs from living and cadaveric-donors which provided the opportunity for different countries in the Middle East to organize cadaveric and living-donations.\textsuperscript{16}

The awareness and knowledge about transplantation of human organs was high among the study participants as compared to the study done in Pakistan,\textsuperscript{29} where 84.5% of our respondents claimed that one can donate several organs other than kidneys and liver, while only 5% suggested that transplantation is limited to the kidneys only. This hints that a good population of Iraqi young adults are preoccupied about the possibilities to procure several organs to save lives and do some unpopular but possible transplantations and further research is suggested to assess their willingness to accept different organs donations and the specific reasons for not willing to, as for the study which was conducted in Australia and showed willingness to donate all organs except the eyes as a result of donors’ concerns of disfigurement.\textsuperscript{30}
Iraqi constitution clearly legislated a law that illegalize trading organs in Iraq and declared a strict and aggressive punishment for this act. However, more than half of the participants (55.2%) had no idea about it. Furthermore, 56.9% are accepting the idea of trading in organs. These findings might explain the estimation of several thousand patients from the Arabian Gulf countries have received kidneys sold in Iraq and other developing countries in Middle East and South Asia. It is not surprising, therefore, that this practice of trading in human organs has alarmed the medical profession, the public and many governments and it has rightly been condemned by all major religions and by most transplantation societies including the International, European, American and the Middle Eastern Society for Organ Transplantation.

From the authors’ point of view, the main limitations to start deceased-organ transplantation in Iraq is the trivial governmental act for initiation an active program and agency to regulate organs donation despite the increasing needs globally and specifically in Iraq. Secondly, the lack of knowledge on this topic in both religious and legal aspects among Iraqi young adults which superimpose.

Conclusion

Most of the participants in the study are convinced with the idea of donating their organs after death and are willing to sign for organs donation program, thus hereby we strongly recommend start building the infrastructure for an agency with several local committees within various governmental health directorates responsible for the regulation of organs donation and allocation, formatting the waiting list and design donors’ cards.

The hesitancy to donate organs was attributed mostly to religious and lack of knowledge issues, and so the initiation of several governmental-supervised campaigns that aim spread the proper knowledge about organs donation and transplantation in both religious and legal aspects would be of a great benefit, along with conducting effective studies and receiving feedbacks from the participants to evaluate these campaigns.

Limitations

This study was conducted during the COVID-19 quarantine and through an online questionnaire on social media, an issue which restricts the participants to only those who are frequently using social media platforms. Furthermore, it provides a general view about the attitudes and perceptions of young adults only and more research is recommended to include other age groups. The reasons behind accepting and rejecting the concept of organs donation were not assessed, giving a crude profile for the overall donation rate in this study.

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