

Saudi Parents' Knowledge and Attitude Towards Pediatric Organ Donation in Al-Riyadh, Kingdom of Saudi Arabia

Abstract

Background: Organ donation is a life-saving process of removing an organ or tissue surgically from one person (the organ donor) and placing it into another person (the recipient). As well as The demand for organ donation is increasing over time Thus, understanding the attitudes and beliefs associated with parental decision making improve the rate of transplantation.

Aims: To Evaluate the perception of Saudi parents towards pediatric organ donation, and to assess the role of cultural and religious beliefs in the parental decision-making regarding organ donation, and to discover the misconceptions leading to the refusal of organ donation.

Methods: A cross-sectional study was conducted in Riyadh region from 1 July 2020 to 31 August 2020 among all Saudi parents aged 18-60 years in Riyadh at the kingdom of Saudi Arabia via an online questionnaire, the responses were Statistically analysis using R v 3.6.3. The mean \pm standard deviation was used to summarize the distribution of continuous variables. Chi-square test of independence was used to assess the association between categorical variables. Linear regression was used to assess factors associated with knowledge regarding organ donation.

Results: Among 588, the majority of responses, female 91.5%, showed that better education was associated with knowing about organ donation in children, with 60.7% of respondents who completed university education reporting so compared to 49.6% of those who completed high school education or more minor. Socio-economic status showed a statistically significant association with knowledge score ($B = 0.36$, $P < 0.05$). Moreover, higher education level showed a statistically significant association with accepting organ donation from one's child ($OR = 1.77$, $P = 0.05$), in contrast to age, gender, and the number of children were not associated with organ donation acceptance. Respondents who did not think organ donation was permissible in Islam were less likely to accept organ donation than respondents who believed it was permissible ($OR = 0.05$, $P < 0.001$). More than half of the respondents heard about organ donation for children after death. At the same time, less than half of the respondents knew the correct definition for brain death. Only 34.7% of respondents knew that organ donation is allowed starting from birth. Most respondents knew about the possible organs to donate except for the lung. In addition, 45%

of the respondents are either agreed or strongly agreed to discuss organ donation with their partner if they faced child loss.

Conclusion: This study found a lack of knowledge regarding organ donation among parents and impressively shows that the parents are willing to discuss organ donation if they face child loss. there was an urgent need to introduce campaigns focussing on awareness of child organ donation, including the protocol used in Saudi Arabia, especially among low socioeconomic status and who do not know Islam permission

Background

Organ donation is defined as the process of removing an organ or tissue surgically from one person (the organ donor) and placing it into another person (the recipient)¹. It has become a successful worldwide treatment for many illnesses and sometimes a cure². More than 150 children die annually while awaiting organ transplantation in the United States and Europe³. The worldwide demand for organ transplantation outnumbers the number of organs available⁴. In Saudi Arabia, Children aged from 0-15 years old represent 30.3% of the population in 2020⁵. With an increasing demand for transplantation globally, organ shortage represents a major obstacle preventing further transplantation in the Kingdom⁶.

Pediatric donation is still a little-discussed topic in academic circles and in the media around the world³. Understanding factors that influence parental decisions has been demonstrated to improve both the success rate of gaining consent and the number of organs actually retrieved^{1,2,3}.

This study aims to evaluate the perception of Saudi parents towards pediatric organ donation, And to assess the impact of cultural and religious beliefs in parental decision making regarding organ donation, and to discover the misconceptions leading to the refusal of organ donation.

When reviewing the literature, limited research papers spot the light on pediatric organ donation. To our knowledge, this is the first study to assess the parent's perception of pediatric organ donation in Saudi Arabia. Thus, this paper will provide needed knowledge about the current perception of pediatric organ donation in Saudi parents.

Methodology

Study design

A cross-sectional study was conducted in Riyadh region from 11 July 2020 to 31 August 2020 including all parents aged between 18 and 60 years that have a children below 15 years old . An online questionnaire was used for data collection. The questionnaire included an initial set of questions to assess the socio-demographic characteristics of the respondents including age, gender, education, number of children and monthly income. Two questions were used to assess knowledge regarding organ donation and the source of information. The second section of the questionnaire included six items to assess the knowledge of the respondents towards pediatric organ donation.

Statistical analysis

Statistical analysis was performed using R v 3.6.3. Counts and percentages were used to summarize the study variables. The mean \pm standard deviation was used to summarize the distribution of continuous variables. Chi-square test of independence was used to assess the association between categorical variables. Linear regression was used to assess factors associated with knowledge regarding organ donation. Respondents were awarded one point for each one correct answer. The question related to possible targets of donation was excluded from the analysis as it was a check-box question. A maximum possible score of five was available. Age, income, and number of children were included as linear (continuous) variables to assess the effect for each one level increase in these variables in knowledge regarding organ donation in children. Binary logistic regression analysis was used to assess factors associated with accepting organ donation from one's child. Hypothesis testing was performed at 5% level of significance.

Results:

The study questionnaire was completed by 588 respondents from Riyadh region (Table 1). Females and males represented 91.5% and 8.5% of the study sample, respectively. Respondents younger than 50 years of age represented slightly more than three quarters of the study population.

Regarding education, university graduates represented 70% of the study sample and respondents who completed only high school represented 16.7%. One-third of the respondents had five children or more. The average monthly income was more than 15000 SAR in 28.9% of the respondents. However, 12.1% reported a monthly income < 5000 SAR. Respondents who earned 5000 – 10000 and 10000 – 15000 SAR represented 28.1% and 31% of the study sample, respectively. More than half of the respondents heard about organ donation for children after death. Most source of information among respondents who heard about organ donation, was social media was the source in 41% and TV programs were the source in 33%. Figure 1

This study showed lack of knowledge regarding organ donation in children (Table 2). Less than half of the respondents knew the correct definition for brain death (n = 245, 41.7%) and only 39.5% (n = 232) knew that the brain function can not be restored after death. Only one-third of the respondents knew that organ donation is allowed starting from birth (34.7%, n = 204) and 26.9% (n = 158) know the correct time window to harvest organs for donation after death.

The majority of respondents knew that kidneys and liver can be donated after death (89.5% and 82.8%, respectively). Three-quarters of the respondents knew that the heart can be donated (76.7%). Only 51.7% and 61.1% knew that the lung could be donated after death, respectively.

Participant attitudes showed that 45% of the respondents either agreed or strongly agreed to discuss organ donation with their partner if they faced child loss and 25% disagree or strongly disagreed. On the other hand, 21% of the respondents showed refusal towards organ donation as they believed it would take a lot of time while 40% disagreed. Similarly, 20% of the respondents showed refusal towards donating their children organs to someone they did not know. While only 12.1% (n = 71) of the respondents ever discussed organ donation with their children. The suitable age for such discussion varied across respondents with 65.5% preferring the children to be > 18 years before such discussion. The remaining 26.9% and 7.48% chose 13 – 17, and 6 – 12 years old,

respectively. Less than three-quarters of the respondents were ready to accept organ donation if there is need for it and only 28 (4.79%) refused. On the other hand, Only half of the respondents accepted the idea of donating their child's organ if they faced such a loss. However, 44.4% were ready to change their opinion based on the wishes of their children (Figure 2).

Table 1. Socio-demographic statistics of the study sample

| | |
|---|--------------|
| | [ALL] |
| | N=588 |
| Gender: | |
| Female | 538 |
| Male | 50 (8.50%) |
| Age: | |
| 18-29 | 99 (16.8%) |
| 30-39 | 169 |
| 40-49 | 198 |
| 50-60 | 113 |
| >60 | 9 (1.53%) |
| Education level: | |
| Bachelor's degree | 406 |
| Master's / Doctorate degree | 67 (11.4%) |
| High school degree | 98 (16.7%) |
| Secondary school degree | 17 (2.89%) |
| Number of children: | |
| One child. | 97 (16.5%) |
| Two children | 71 (12.1%) |
| Three children. | 95 (16.2%) |
| Four children | 119 |
| Five Children or more | 206 |
| Monthly income: | |
| Less than 5000 | 71 (12.1%) |
| 5000-10000 | 165 |
| 10000-15000 | 182 |
| More than 15000 | 170 |
| Ever heard about organ donation for children | |
| No | 244 |
| Yes | 344 |

Figure 1. Source of information regarding organ donation

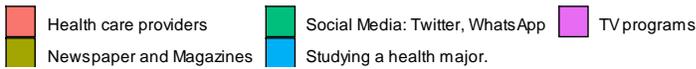
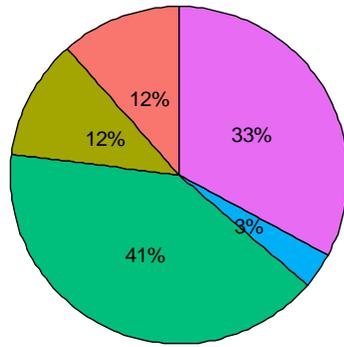
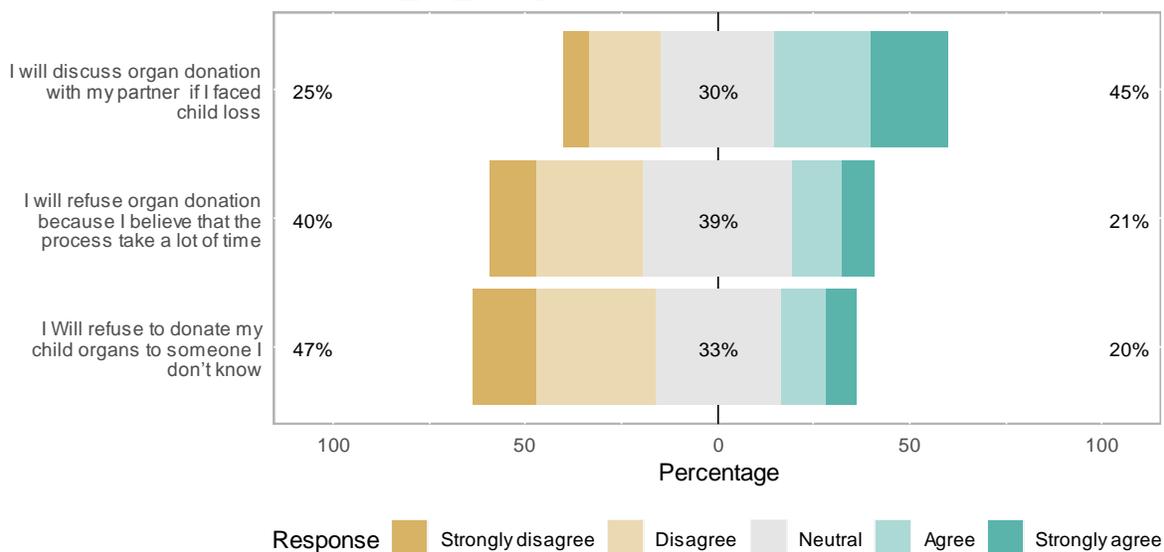


Table 2. Knowledge regarding organ donation

| | [ALL] N=588 |
|--|----------------|
| Definition of brain death | |
| Brain death is the cessation of all brain functions, including the brain stem, with an opportunity to restore normal functions | 123 (20.9%) |
| The cessation of some brain functions, without the brain stem being affected, with the opportunity to recover its normal functions. | 115 (19.6%) |
| The irreversible cessation of some brain functions, without the brain stem being affected, with no chance of restoring its normal functions. | 105 (17.9%) |
| <u>The irreversible cessation of all functions of the entire brain, including the brainstem. With no chance to regain its normal functions</u> | 245 (41.7%) |
| There's no chance for a brain death patient to restore normal brain function: | |
| <u>I agree</u> | 232 (39.5%) |
| I disagree | 96 (16.3%) |
| I don't know | 260 (44.2%) |
| In which age is it allowed to donate organs after death ?: | |

| | |
|---|----------------|
| From 7 to 18 years old | 103 (17.5%) |
| From one to 6 years old | 99 (16.8%) |
| Older than 18 years old | 182 (31.0%) |
| <u>Since birth</u> | 204 (34.7%) |
| What is the appropriate time window to harvest organ for donation after death?: | |
| 13-24 hours | 55 (9.35%) |
| <u>6-12 hours</u> | 158 (26.9%) |
| I don't know | 361 (61.4%) |
| More than 24 hours | 14 (2.38%) |
| Correct answers are underlined Counts and percentages were used to summarize the responses | |

Figure 2. Attitudes towards organ donation



Discussion:

The current study investigated Saudi parents' attitudes towards pediatric organ donation after death. This study aims to Evaluate parental perception towards pediatric organ donation And explore the role of cultural and religious beliefs in parental decision making .as well as discover the misconceptions leading to the refusal of organ donation.

In the current study, the impact of social media played a significant role in the source of information. 41% of Saudi parents had heard of pediatric organ donation through (Twitter, Snapchat, WhatsApp) followed by tv programs 33%. In contrast, a study conducted in turkey were most of the parent's source of knowledge from Tv programs was 35% ⁴. At the same time, the lowest percentage in both Saudi Arabia and Turkey are health care providers and newspapers (12% in Saudi Arabia, 15%, 7.7% in Turkey)⁴. In comparison to study done in the southeastern United States. Family members were the most source of information⁷.

Accepting organ donation from one's child in the current study was associated with higher education parents (OR = 1.77, P = 0.05), In contrast to the united states were linked with lower education level 83.3 % ⁷.

There is a slight misconception of the brain death definition in the present study. this study shows near to half of the parents knows the definition of brain death 41.7% while surprisingly 70.9% in turkey⁴, as well as 47.1% in the United States ².

There is a conflict of the chance of the brain to restore its function. In our study, 39.5% agree that there is no chance of restoring brain function, while 44.2 do not know. In comparison to turkey, 16.2% believe that it might restore and this is affecting their decision⁴ and 45.4% in the United States ².

Most parents are worrisome about donating to child patients who's not know them, which impacts their decision-making. In this study, 47% refuse donation to a stranger child patient. While in Turkey, 7.5% of parents will agree to donate if they know the child's patient.⁴

Regardless Of the general population being both aware and overall supportive of organ donation, these views can change when it comes to decision-making in a critical situation about a child ¹. Family consent to donation is affected by a set of varying cultural, personal, religious, demographic, and healthcare professional factors⁸.

Regarding the causes of refusal, 48% do not want their child to suffer after death. Similarly, a study was done in England 36.3%¹. Regarding the time length of the process, 21% of parents refuse for this reason, almost similar to 27.2 in England study.

In addition, 47% of the respondents showed refusal towards donating their children's organs to someone they did not know. In contrast to turkey 58.1 were willing to donate to a stranger⁴.

Many parents doubted whether organ donation was permissible in Islam or not. The results showed that 52% of the respondents did not know whether organ donation was permissible in Islam, and only 44% agreed. In contrast, to turkey, 7.9% were known the fatwa of permission⁴.

Respondents who did not think that organ donation was permissible in Islam were less likely to accept organ donation than respondents who thought that it was permissible (OR = 0.05, P < 0.001). similarly, in turkey⁴.

Conclusion:

This study found a lack of knowledge regarding organ donation among parents and impressively shows that the parents are willing to discuss organ donation if they face child loss. There was an urgent need to introduce campaigns focussing on awareness of child organ donation, including the protocol used in Saudi Arabia, especially among low socioeconomic status and who do not know Islam permission

Limitations

The main strengths of this study it is rarely to conduct sensitive topic like pediatric organ donation among Saudi parents. furthermore, the sample size it's large and representative. This study shows limited data about the impact of children wishes on parent decision making

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