

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

Abstract

Background: Organ donation is the 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 and the major limiting factor in transplantations is the lack of available donors

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' was Statistically analysis using R v 3.6.3.

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 less. Socio-economic status showed a statistically significant association with knowledge score ($B = 0.36, P < 0.05$) ,Higher education showed a statistically significant association with accepting organ donation from one's child ($OR = 1.77, P = 0.05$) , Results showed that age, gender, and number of children were not associated with accepting organ donation .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 ($OR = 0.05, P < 0.001$). More than half of the respondents heard about organ donation for children after death. 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 of respondents knew about organ that can be donated except for the lung. 45% of the respondents either agreed or strongly agreed to discuss organ donation with their partner if they faced child loss. furthermore, 87.9% of respondent refuse to discussed organ donation with the their children while 44.4% were ready to change their opinion based on the wishes of their children .moreover, 69.7% ready to accept organ donation if there is need for it. 52% of the respondents did not know whether organ donation was permissible.

Conclusion: This study found lack of knowledge regarding organ donation among parents and shows parent 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 socio-economic status and who don't knew 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 cure. In the Kingdom of Saudi Arabia Children represent 40% of the population (8,119,477) in 2018 and the demand for organ donation is increasing over time and the major limiting factor in transplantations is the lack of available donors.

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 the parental decision making regarding organ donation , and to discover the misconceptions leading to the refusal of organ donation.

When reviewing the literature, there were no studies focused on the same issue of this paper. Thus, this paper will provide a 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. 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 – 1000 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%.

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.

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	

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 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.

Discussion :

- Source of information

The impact of social media play a major role in our study were 41% had heard of pediatric organ donation through (twitter, snapchat, whatsapp...)and 33% through tv program. in contrast, study done in turkey were most of parents source of knowledge from tv programs 35%². While the lowest percentage in both Saudi Arabia and turkey are health care providers and newspaper (12% in Saudi Arabia , 15% , 7.7% in turkey).²

- Demographics variation

In the present study, we investigated Saudi parents' attitudes towards pediatric organ donation after death. We found that most of our study subjects were females. In agreement to our study, a study from Italy by Pileggi et al. also observed high numbers of mothers responding to study in comparison with fathers³, highlighting mothers as the prime source of knowledge for the family and one who takes care of the household's health.

We also evidenced that most of the parents who participated and responded had an age cohort of >30 years and had >5 children in our study. This indicates that

younger parents with new experience in parenthood might have a role to play in forming an opinion regarding pediatric organ donation after death. In addition, including educational level as 69.0% of the parents were graduates in current study.

Therefore, women should be targeted for awareness programs regarding deceased pediatric organ donation

- Knowledge of OD

There is a slight misconception of brain death definition. this study shows near to half of parents knows the definition of brain death 41.7% while surprisingly 70.9% in turkey ².

There is conflict of the chance of brain to restore its function again, in our study 39.5% agree on there is no chance to restore the brain function while 44.2 they don't know. In comparison to turkey 16.2% they believe that it might restore and this is effect on their decision.²

Most parents shows worrisome about donate to child patient whose not know them and that impact on their decision making. In this study 47% refuse donation to stranger child patient. while in turkey 7.5% of parents will agree to donate if they know the child patient.²

- Attitude and Factors affecting decision making of organ donation.

Regardless Of the general population being both aware and overall supportive of organ donation, when it comes to decision making in a critical situation about a child, these views can change(6HS). Family consent to donation is known to be affected by a set of varying cultural, personal, religious, demographic and healthcare professional factors (15).

The study questionnaire was completed by 588 respondents from Riyadh region (Table 1).

In this study we aimed to address and assess the role of cultural and religious beliefs in the parental decision making regarding organ donation, our results showed that beside the religious and cultural beliefs the misconceptions and lack of knowledge is a leading reason for the refusal. While the higher educated parents were more likely to accept organ donation and discuss it with their partner and child, and they were prepared to change their opinions based on their child's desires.

According to the age , previous studies shows that children under the age of five were less likely to be referred for donation unlike children over the age of ten. ¹

The readiness of the participants to donate the child's organ if there is a need is 50.2% and the refusal was 49.8%. Regarding the causes of refusal 48% do not want their child to suffer after death while 21% of the respondents showed refusal towards organ donation as they believed it would take a lot of time, Similarly , 47% of the respondents showed refusal towards donating their children organs to someone they did not know , and the others were in doubt whether organ donation was permissible in Islam or not and the results showed that 52% of the respondents did not know whether organ donation was permissible in Islam and 44% agreed while only 4% disagreed. Respondents who did not think that organ donation was permissible in Islam and who were not sure were less likely to accept or donate an organ than respondents who knew that it was permissible. Around 70% of the respondents are ready to accept organ donation if there is a need for it. On the other hand 50% only are willing to donate a child's organ if there is a need for it. (there is a gap of 20%, what is the explanation?) And about 44% are willing to change their opinion based on their child's own wishes.

Conclusion: This study found lack of knowledge regarding organ donation among parents and impressively shows that the parents 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 socio-economic status and who don't 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

COMPETING INTERESTS DISCLAIMER:

Authors have declared that no competing interests exist. The products used for this research are commonly and predominantly use products in our area of research and country. There is absolutely no conflict of interest between the authors and producers of the products because we do not intend to use these products as an avenue for any litigation but for the advancement of knowledge. Also, the research was not funded by the producing company rather it was funded by personal efforts of the authors.

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