

FACTORS AFFECTING CONSENT BY FAMILIES FOR BEATING HEART ORGAN DONORS-A PILOT STUDY, AT HEART TRANSPLANT DEPARTMENT OF AFIC-NIHD

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Contribution

All the authors contributed significantly to the research that resulted in the submitted manuscript.

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ABSTRACT

Objective: To study the response of donor families regarding beating heart organ donation and document effect of counseling, education and residence on consent.

Methodology: This Quasi experimental Study was conducted from 1st June 2011 to 1st December 2012 at Armed Forces Institute of Cardiology-National Institute of Heart Diseases and three donor hospitals of Rawalpindi. Donor families were approached by psychologist. Effect of counseling, education, residence and reasons for refusal were documented.

Results: 27 donors were offered in 18 months with mean age of 28.22 ± 8.86 years. 88.9% (n=23) were males and rest were females. 16 (59.2%) had a history of road traffic accident and 7 (25.92%) presented after fall. About 48% (n=13) belonged to urban areas and rest to rural. 9 (33%) families were uneducated, 8 (30%) didn't complete secondary school and 10 (37%) had completed secondary school or higher school. First response to organ donation was yes in 1; no in 24 where as 2 families became aggressive. After counseling 1 family agreed to donation and 6 agreed to concept of donation but didn't donate. 37.4% (n=10) families didn't accept the brain death. In 9 families 14.8% (n=4) considered it un-Islamic, 11.1% (n=3) considered it will mutilate body, 7.4% (n=2) remained aggressive. Education was statistically significant for consent ($p=0.049$) whereas area of residence was not ($p=0.33$).

Conclusion: Our study shows that counseling and education of families of heart organs donors are important factors affecting consenting process.

Key Words: Organ Donation, Beating Heart Donor, Counseling

INTRODUCTION

Organ availability for donations has always been a dilemma, there being a significant gap between availability of organs and patients for whom organ transplantation is the last treatment option. In USA on average, 18 people die every day whereas around 1000 people die in UK each year waiting for transplant.¹ Refusal of consent is an issue all over world even in the countries with proper organ procurement organizations and centralized organ allocation systems. In UK audit of death demonstrated a consent rate of 63% for Beating heart donor and 57% for donation in non-beating heart donor for the period 2007-9.² The situation is worse in third world countries where even the development of a proper donor program is hampered by socio cultural, religious, legal and other factors.

In Pakistan Human organ transplant bill was passed in 2009 to improve organ transplantation and prevent organ trade.³ Since then efforts are being made to increase the organ donation especially by increasing beating heart donors. Despite a great improvement in transplantation law, there remain several barriers regarding notification of brain and cardiac death as well as completion of the donation process. This is due to difficulties in obtaining consent from families.⁴⁻⁶ Due to lack of knowledge about organ donation it is virtually impossible to estimate the time needed by families to understand and accept brain death and to identify the grief sequence in order to avoid family refusals.⁷ A joint effort of transplant physicians/surgeons with religious scholars is needed to formulate a "considered opinion" in enforcing the laws related to organ transplantation in Pakistan.⁸

We sought to investigate the responses of families to counseling to consent for organ donation.

METHODOLOGY

A Quasi experimental study was carried out from 1st June 2011 to 1st Dec 2012 after approval by the Ethical review board of AFIC-NIHD and donor hospitals. The population consisted of all donors offered to heart transplant department of Armed Forces Institute of Cardiology-National Institute of Heart disease by donor hospitals. Donors were defined as the patients declared brain dead and were kept ventilator by the donor hospitals where as donor hospitals were the local tertiary care hospitals with facility of ventilators, Intensive care units and neurosurgery departments willing to participate in study. The information regarding age, gender, place of residence, education status of family members, cause of brain death, Blood group and Ejection Fraction on echocardiography provided by donor hospitals was used to fill the performa.

A trained clinical psychologist not having any conflict of interest was sent to donor hospital for counseling of donor

families. The psychologist assessed the first response of the families to the question of organ donation. The families who said no they were provided reading material regarding the passing of HOTA law in Pakistan, concept of and fatwas on brain death and organ donation by Saudi Arab grand council and Iranian Supreme council.² Families were allowed to interact and ask questions to clarify their concepts. The counseling was done for 2 sessions of one hour repeated after 8 hrs and the question of organ donation was again repeated.

The data recorded was entered in SPSS version 17. The Frequencies and percentages were defined for qualitative variables (gender, education, residence, cause of brain death) whereas range, mean with standard deviation was described for quantitative variables (age, weight, ejection fraction). Pearson Chi-Square was applied to see the effect of education and residence of donor families on consent for organ donation. A P-value of ≤ 0.05 was considered significant.

RESULTS

Total of 27 donors were offered from three donor hospitals of Rawalpindi city in a period of 18 months. The ages of the donors offered ranged from 15-40 yrs with a mean of 28.22 ± 8.86 yrs, with more than 70% of donors under age of 35 yrs. 88.9% (n=23) of them were males while only 11.1% (n=4) females. The weight of donors ranged from 20 kg to 95 kg with mean of 65.4 ± 14.99 kg (Table 1). 16 (59.2%) of donors had a history of road traffic accident with head injury, 7 (25.92%) presented with head injury after fall, 3(11.1%) were brain dead with space occupying lesion brain whereas 1(3.7%) after being run over by train.

About 48% (n=13) of donors and their families belonged to urban areas where as 51% (n=14) belonged to rural area. 33% (n=9) of family relatives with the donors were uneducated, 30% (n=8) didn't complete secondary school education and only 10 families (37%) had completed secondary school or higher school education.

Echocardiography was done by cardiologist in all donors to assess the LV function which showed Ejection Fraction ranging from 20 to 65 with a mean of 54.81 ± 10.23 (Table 1).

The first response to the question of organ donation was yes for donation in just 1(3.7%), it was no in 24(88.9%) where as about 2 (7.4%) of families became aggressive said don't know and don't care. After counseling the question was repeated again and response showed that one more family agreed to organ donation after counseling session and 6 of families agreed to concept of organ donation but didn't donate. 37.4% (n=10) families didn't accept the brain death even after counseling. Apart from lack of acceptance of

Table 1: Demographic Profile

Variables		Age in years	Weight in kg	EF on ECHO
Mean		28.22±8.868	65.44±14.991	54.81±10.236
Minimum		15	20	20
Maximum		49	95	65
Percentiles	10	17.80	49.00	41.00
	20	19.00	55.60	53.00
	30	21.00	60.00	55.00
	40	25.00	65.00	55.00
	50	26.00	65.00	60.00
	60	30.00	69.00	60.00
	70	35.00	73.60	60.00
	80	37.00	78.80	60.00
	90	40.00	85.00	60.00

brain death, in rest of 9 donor families 14.8% (n=4) considered it against the Islamic faith, 11.1% (n=3) considered it will mutilate body, 7.4% (n=2) remain aggressive and said don't know and don't care.

Family education showed an association with response after counseling session as none out of 9 uneducated, 3 out of 8 under matric (not completed secondary school education) and 5 out of 10 matric and above (completed secondary school or higher school education) agreed to concept of organ donation (Pearson Chi-Square P-value 0.049), whereas area of residence of family of donor had a no significant effect on consent (Pearson Chi-Square P-value 0.33) (Table 2), (Figure 1), respectively.

DISCUSSION

Consent for organ donation whether by donors themselves or their families is a difficult consent to obtain.² The paucity of donors offered worldwide has been shown in many studies. Our study population consisted of 27 brain dead offered during 18 months from three donors hospitals which is similar to a retrospective study done in Brazil done from January 2008 to December 2010 where there were 41 brain death cases were offered.⁴ In our study the ages of the brain dead donors offered ranged from 15-40 years with a mean of 28.22 ± 8.86 years, in India in a similar study showed median age of 46 years.⁹ Although in our study gender showed no effect on consent rates (59% vs. 53%, p = 0.12) whereas Indian study showed a consent rate more in brain dead females.¹⁰

There is wide international variation in rates of consent. In our study 2 (7.4%) families consented to organ donation out

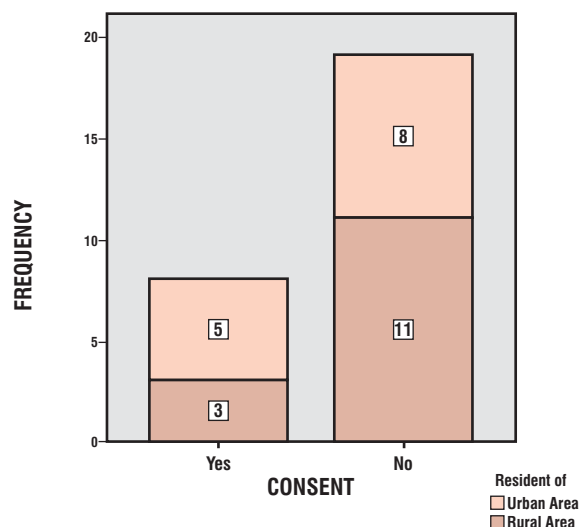
of 27. A similar study showed a consent rate of families was 19.5% (out of 41 brain dead) 41.6% (out of 125 brain dead) and 31% in Brazil, Iran and Netherlands respectively.^{4,5,11}

The diagnosis of brain death and perception that death varies from person to person and is intricately linked to the issue of organ donation and may influence family members' decision making. Many studies have consistently shown that poor knowledge and understanding of brain death is common is the most common cause of consent refusal.¹² Apart from lack of acceptance of brain death n=26 (35.6%), belief in miracle and patient recovery (n=22; 30.1), fear of gossip regarding organ sale rather than autonomous organ donation (n=11; 15.1%), and fear about deformation of the donor's body (n=9; 12.3%) were found to be cause of consent refusal.⁵ Protecting the dead body, which related to keeping the body whole and intact was the most frequently quoted reason for refusal.¹³

Table 2: Effect of Education on Consent for Organ Donation

Age in years	Consent	
	Yes	No
Uneducated	0 (0%)	9 (47.4%)
Not Completed Secondary School Education	3 (37.5%)	5 (26.3%)
Completed Secondary School or Higher School	5 (62.5%)	5 (26.3%)

Figure 1: Effect of Area of Residence on Consent for Organ Donation



Studies have identified quality of communication during the request (AOR, 12.39; CI, 7.76-20.02), families knowledge about organ donation (AOR, 10.01; CI, 6.47-15.50), as well as patient and family socio demographic characteristics (AOR, 3.32; CI, 2.01-5.48) playing an important role in consenting process.¹⁴

Studies suggest modifiable factors in the process of requests for organ donation, in particular the skills of the individual making the request and the timing of this conversation having a significant impact on rates of consent.^{15,16} That's why in developed countries there are specialized coordinators or psychologists trained to interact with the families.

A meta-analysis shows a 5% increase in organ donation by public education through campaigns as compared to baseline or a control group and Public education is recommended to correct misconceptions.^{17,18}

The major limitation of the study is that the sample size is too small to be applied to whole of population. But with the law just implemented the situation may will improve in few years to come as there is lack of awareness about organ donation among the physicians around the country.¹⁸

All said, the authors feel that although difficult but by increasing awareness and education population and with proper counseling techniques the consent for beating heart donation is possible.

This study shows that diverse social religious issues in Pakistan the concept of organ donation is still new for mass population. There is an urgent need for better education at mass level about organ donation and brain death definitions. The religious scholars through the transplant physicians and

surgeons can also be immense help in this regards to enforce the law and making transplant possible in Pakistan.

CONCLUSION

Our study shows that counseling and education of families of heart organs donors are important factors affecting consenting process.

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