



Role of Coordinator-Donor Conformity and Personalized Case Selection in Success Rate and Quality of Family Consent

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Abstract

Introduction: Regarding to ethnicity and racial complexity in socially heterogeneous and refugee-accepting countries, family approach for organ donation request from a deceased donor could be unpredictable. The problem could be settled by adherence to coordinator-donor conformity rule besides principals of donor family care.

Methods: In our OPU, we have recruited a considerable quantity of organ donation coordinators (mainly medical students) with different ethnicities, dialects, and personality types. In this study, we have assessed family approach success indices in two different eras (Before 2017 and after this time). These included overall family consent and refusal rates, time interval from the first interview to actual donation, the weight of different age clusters in the donor pool and etc.

Results: Considerable progress was achieved in all family approach success indices. Overall family consent rate was found to be increased from 61% in the first era to 88% in the second era ($P = 0.005$). The mandatory time for the coordinators to obtain family consent dropped significantly. (12.2 ± 8.6 to 6.3 ± 4.8 Hr, $P = 0.02$). Furthermore, the weight of precious young donors (< 40 years) increased from 36% to 47% ($P = 0.05$) due to more success rate in more difficult young cases.

Conclusions: Appropriate recruitment of organ donation coordinators warranties more successful organ donation efforts after proper training. Decision making about suitable usage of every coordinator in a specific part of the family approach stages should be done case-by-case. This strategy could be of great benefit in ethnicity and cultural variant communities.

INTRODUCTION

Solid-organ transplantation is the last rescue option in end stage organ failure. Although there are several limitations belonging to transplantation including the risk of infection and rejection. Many attempts have been done to improve regenerative medicine, but none of them have made the therapeutic approach, free of organ donation [1]. Organ shortage is a significant drawback in the transplantation process [2, 3]. Over the past five years, the number of deceased organ donors in Iran has increased by 30% [4]. This progress was the result of

improved approach to next of kin, donor identification and extended donor criteria based on national practice guidelines. Several factors influence the last decision regarding donation. Subsequently consent rate is varied in different organ procurement units (OPUs). Donor-related factors include donor's gender and age, ethnicity, race and willing to donation are some considerable items which could be approached [5]. In a study conducted by our team, a great proportion regarding causes of refusal for organ donation was denial of brain

death (44.4% in 2009), which decreased to 12.7% in 2016 [6]. However, in this period, there was a 40% increase in religious believes as a cause of family refusal. Due to ethnicity and racial complexity in socially heterogeneous and refugee-accepting countries, family approach for organ donation request from a deceased donor could be unpredictable. The problem could be settled by adherence to coordinator-donor conformity rule besides principals of donor family care. Considering that obtaining consent for donation from a brain death family is the most important part of a successful transplantation program, persuading the suspicious people is a challenge yet. In this regard, studies have shown that young people with no medical risk factors are less likely to be donors than older ones with the history of several comorbidities [7, 8]. Hence, obtaining the consent of families, who are reluctant to donate organs, may increase ideal donors. In this regard, procurement coordinators are the key members of the donation team. In case of exposing a trustworthy coordinator as a negotiator for organ donation, donor families have this opportunity to argue their ambiguities and doubts which prevent donation. Requesting consent for donation is a dynamic process which needs reproaching again and again. Interviews with non-donor families show that a person who refuses to donate, would not make the same decision regarding donation again [9, 10], so, the last decision to refuse donation is not based on deeply believes and might be influence by factors. Procurement coordinators have more knowledge about donation than other staff; therefore, relatives interested in knowing more are more likely to be an organ donor family.

METHODS

This study was performed in OPU of Masih Daneshvari Hospital of Shahid Beheshti University of Medical Sciences. This OPU covers 1/3 population of Tehran for identification of brain-dead cases and potential donors. After the detection of a potential brain-dead donor, procurement coordinator would visit the patient to evaluate both the accuracy of brain death and quality of organs. Then a trained coordinator would contact to next of keens and open the discussion regarding donation. In this cohort study, some indexes regard to success in family approaches were evaluated in two different periods of time based on our policy for getting consent of organ donation. All procurement coordinators were evaluated to identify their race, religious, ethnicity, and local dialect. From 2015, we gathered data related to family consent program including 1- weight of different age clusters in donor pool, 2- donor's gender, 3- family consent rate, 4- time interval from first interview to final positive decision, 5- cause of brain death among actual donors, 6- cause of family refusal, 7- organ per donor rate. After publishing our study in 2017 entitled "Update on Causes of Family Refusal for Organ Donation and the Related Factors:

Reporting the Changes over 6 Years", it was clarified that a big proportion of family refusal was related to religious believers in 2016. So, we changed our policy for assigning proper procurement coordinator for each donor family. In this regard, coordinator-family matching was performed to allocate coordinators based on family ethnicity, religious and local dialect. Afterward, outputs related to these two-time interval were compared from 2015 to 2016 and from 2017 to 2018.

Statistical Analysis

Data were analyzed by SPSS 22 software (SPSS, Inc., Chicago, IL). Quantitative data were expressed as mean SD and qualitative variables were presented in percent. Accordingly, the data were analyzed using the Mann Whitney U test. $P < 0.05$ was considered as significant level.

RESULTS

There was a total of 723 potential donors in the first era and 641 in the second era. Overall actual donor demographic data are summarized in Table 1 and 2. The mean age of actual donors significantly decreased and reached 36.72 y in the second era, whereas it was found to be 43.47 y in the first era. There was no difference in the frequency of different genders and female donors had a proportion of $< 40\%$ in both era. From the cause of death point of view, the trauma had a steady-state pattern (23.3% in the 1st era and 22.9% in the 2nd era), but brain tumors and cerebral vascular attacks (CVA) was found to be statistically dropped and reached 3.8% and 6.8%, respectively. Organ per donor was 2.34 in 2016, while this rated increased to 3.1 in 2018 ($P = 0.05$). Furthermore, consent rate significantly improved and was 88% in 2018 ($P = 0.005$). Additionally, time spent on getting family consent dropped significantly (12.2 ± 8.6 to 6.3 ± 4.8 hours; $P = 0.02$; Table 2).

Table 1. Demographic Data of Actual Donors

Parameter	First Era 2015-2016	Second Era 2017- 2018	P value
Mean age (year)	43.47	36.72	0.01
Gender (Female)	31.1%	36.6%	0.54
Cause of brain death			
Trauma	23.3	22.9	0.36
Brain Tumor	7.1	3.8	0.01
Intoxication	5.7	6.2	0.9
Cranial Bleeding	27.1	35.5	0.7
CVA	13.6	6.8	0.04
Others	23.2	24.8	0.9
Organ per donor	2.34	3.1	0.05

The most prevalent cause of family refusal in the 1st era was religious believes and brain death denial (43.6 and 12.7%, respectively), however, it was religious believes and expectation of a miracle in the 2nd era (26 and 25%;

Table 3). Brain death denial and belief in body integrity had a stable trend after death, but no difference was found in both eras. Concern about organ trade and opposite donor wishes significantly diminished by family donor — coordinator matching system.

Table 2. Donation Process Data

Parameter	First Era 2015-2016	Second Era 2017-2018	P value
Number of potential Donors	723	641	0.34
Actual Donors	418 (57.8)	502 (78.3)	0.12
Consent Rate, %	61	88	0.005
Time consuming to get consent	12.2 ± 8.6	6.3 ± 4.8	0.02

Data are presented as Mean ± SD or No. (%)

Table 3. Causes of Family Refusal in 2 Eras: 2016 and 2018

Cause of family Refusal	First Era 2015-2016	Second Era 2017-2018	P value
Religious Believes	43.6	26	0.012
Expectation of a miracle	10.9	25	0.048
Brain death denial	12.7	9.7	0.74
Concern about organ trade	5.4	2	0.01
Belief in body integrity after death	3.6	1.6	0.06
Opposite donor wishes	5.4	11.7	0.01
Other causes	18.4	12.3	

DISCUSSION

Our study indicated that the mean age of actual donors significantly decreased using family-coordinator matching approach. The trauma had a steady-state pattern, but brain tumors and CVA had fewer quotas. By this approach, organ per donor exhibited an increasing trend. This increase may be due to organ procurement from younger donors. In addition, lower time spent on the family approach led to improve organ quality and donor maintenance. Islam is the dominant religion in Iran, and the law of organ donation from brain death was first passed in 2000 [11]. In our country beyond knowledge and attitude regarding organ donation, the final decision for organ donation is affected by religious leaders' views on organ donation. In some situations, the general population had little knowledge regarding their fatwa and made the wrong judgment. Our study shows that the most prevalent cause of family refusal was religious believes in both eras whereas expectation of a miracle was also an important obstacle for donation. Family donor—coordinator matching approach resulted in decreasing causes such as concern about organ trade and opposite donor because of covering the concerns of the families. Appropriate recruitment of

organ donation coordinators after proper training warranties more successful organ donation efforts. Decision making about a suitable use of coordinator in a specific part of the family approach should be done case-by-case. This strategy could be of great benefit in ethnicity and cultural variant communities [12-14]. In a study conducted by Aghaee et al. only 23.4% of participants have known brain death definition and a larger proportion of participants was unaware of religious leaders' attitude toward organ donation in both Sunni and Shia, while near 90% of religious leaders agree with organ donation from brain-dead cases [15]. In contrast, in another study more than two-thirds of participants were aware of religious leaders' views toward organ donation [16]. In a study conducted by Morgan et al., 11.7% of families with potential donors, who had been registered, have changed their decision. The most important factors belonging to family overrides including 1- failure regarding involvement of a specialist nurse for organ donation in the family approach, in other words, a donor coordinator; 2- donation after circulatory arrest and 3- African-American, Asian or minority ethnicity [17]. Donor coordinator conformity approach could provide effective emotional support for family and emphasize on religious-based values. In General, there are relatively negative attitudes to organ donation among minority ethnic groups in all countries that almost are associated with lack of sense of integration and belonging [18, 19].

CONCLUSIONS

Spiritual leaders from minority groups impact on development of positive attitudes to donation. Informed procurement coordinator would be a modulator in this context. Being familiar with religion and native culture make coordinator able to give some good example of heroes for getting consent of donation. This approach is easy and practical for minorities and immigrants.

REFERENCES

- Ghorbani F, Feizabadi M, Farzanegan R, Vaziri E, Samani S, Lajevardi S, et al. An Investigation of Topics and Trends of Tracheal Replacement Studies Using Co-Occurrence Analysis. *Tissue Eng Part B Rev.* 2017;23(2):118-27. doi: 10.1089/ten.TEB.2016.0254 pmid: 27758155
- de Perrot M, Snell GI, Babcock WD, Meyers BF, Patterson G, Hodges TN, et al. Strategies to optimize the use of currently available lung donors. *J Heart Lung Transplant.* 2004;23(10):1127-34. doi: 10.1016/j.healun.2003.09.010 pmid: 15477105
- Wijdicks EF. Determining Brain Death. *Continuum (Minneapolis, Minn.)*. 2015;21(5 Neurocritical Care):1411-24. doi: 10.1212/CON.0000000000000221 pmid: 26426238
- Sadegh Beigee F, Ghorbani F, Shahryari S, Mojtabae M. Demographic Differences Between Two 7-Year Periods of Organ Donation in Iran: A Single-Center Experience. *Exp Clin Transplant.* 2019;17(Suppl 1):242-5. doi: 10.6002/ect.MESOT2018.P106 pmid: 30777566
- Thomson D, Bookholane H, Du Toit T, McCurdie F, Steenkamp L, Human L, et al. Factors Influencing Deceased Donor Consent Rates in Cape Town, South Africa.

- Transplantation. 2018;102:S113. doi: [10.1097/01.tp.0000542718.06826.7e](https://doi.org/10.1097/01.tp.0000542718.06826.7e)
6. Mojtabaee M, Ghorbani F, Mohsenzadeh M, Beigee FS. Update on Causes of Family Refusal for Organ Donation and the Related Factors: Reporting the Changes Over 6 Years. *Transplant Proc.* 2018;50(1):10-3. doi: [10.1016/j.transproceed.2017.11.021](https://doi.org/10.1016/j.transproceed.2017.11.021) pmid: 29407290
 7. Shafer TJ. Improving relatives' consent to organ donation. *BMJ.* 2009;338:b701. doi: [10.1136/bmj.b701](https://doi.org/10.1136/bmj.b701) pmid: 19383729
 8. Rudge CJ, Buggins E. How to increase organ donation: does opting out have a role? *Transplantation.* 2012;93(2):141-4. doi: [10.1097/TP.0b013e31823a2411](https://doi.org/10.1097/TP.0b013e31823a2411) pmid: 22094956
 9. Rithalia A, McDaid C, Suekarran S, Myers L, Sowden A. Impact of presumed consent for organ donation on donation rates: a systematic review. *BMJ.* 2009;338:a3162. doi: [10.1136/bmj.a3162](https://doi.org/10.1136/bmj.a3162) pmid: 19147479
 10. Simpkin AL, Robertson LC, Barber VS, Young JD. Modifiable factors influencing relatives' decision to offer organ donation: systematic review. *BMJ.* 2009;338:b991. doi: [10.1136/bmj.b991](https://doi.org/10.1136/bmj.b991) pmid: 19383730
 11. Postel J. Simple mail transfer protocol. *Inform Sci.* 1982.
 12. Wakefield CE, Reid J, Homewood J. Religious and ethnic influences on willingness to donate organs and donor behavior: an Australian perspective. *Prog Transplant.* 2011;21(2):161-8. doi: [10.7182/prtr.21.2.2071rgn834573152](https://doi.org/10.7182/prtr.21.2.2071rgn834573152) pmid: 21736247
 13. Lam WA, McCullough LB. Influence of religious and spiritual values on the willingness of Chinese-Americans to donate organs for transplantation. *Clin Transplant.* 2000;14(5):449-56. doi: [10.1034/j.1399-0012.2000.140502.x](https://doi.org/10.1034/j.1399-0012.2000.140502.x) pmid: 11048989
 14. Adekoya A, Desalu O, Onakoya J, Adeyeye O, Aderibigbe A, Adekoya B, et al. Willingness of Nigerians to Donate a Kidney. *Nig Qt J Hosp Med.* 2012;22:282-7.
 15. Aghaee MA, Dehghani M, Sadeghi M, Khaleghi E. Awareness of religious leaders' fatwa and willingness to donate organ. *Int J Organ Transplant Med.* 2015;6(4):158.
 16. Huang J. The "Chinese Mode" of organ donation and transplantation. *Hepatobiliary Surg Nutr.* 2017;6(4):212-4. doi: [10.21037/hbsn.2017.07.08](https://doi.org/10.21037/hbsn.2017.07.08) pmid: 28848741
 17. Morgan J, Hopkinson C, Hudson C, Murphy P, Gardiner D, McGowan O, et al. The Rule of Threes: three factors that triple the likelihood of families overriding first person consent for organ donation in the UK. *J Intensive Care Soc.* 2018;19(2):101-6. doi: [10.1177/1751143717738194](https://doi.org/10.1177/1751143717738194) pmid: 29796065
 18. West R, Burr G. Why families deny consent to organ donation. *Aust Crit Care.* 2002;15(1):27-32. doi: [10.1016/s1036-7314\(02\)80041-8](https://doi.org/10.1016/s1036-7314(02)80041-8)
 19. Hulme W, Allen J, Manara AR, Murphy PG, Gardiner D, Poppitt E. Factors influencing the family consent rate for organ donation in the UK. *Anaesthesia.* 2016;71(9):1053-63. doi: [10.1111/anae.13535](https://doi.org/10.1111/anae.13535) pmid: 27440055