

Barriers to Organ Donation: A Study in Alor Setar, Malaysia

Nur Zainie Abd Hamid, Narehan Hassan, and Mohd Rizwan Huzaimi Saidin

Abstract— This study was to examine the influence of factors influencing organ donation decision with the willingness to donate organ. This study was conducted by taking into consideration three factors; awareness, recipient characteristics and public perception toward organ donation. The type of research employed was cross-sectional study where 116 respondents were approached conveniently in selected accessible shopping malls at Alor Setar, Malaysia. The finding indicated that, all (100%) respondents were aware and having an idea about organ donation. Unfortunately, 78.44% believed that organ donation may bring risk to health status and 87.93% hold a negative perception that there will be a great possibility of the donated organ to be misused by irresponsible individuals, especially in the case of ‘black market selling’. Besides, it is also proved that, the decision to involve in organ donation was influence by family members and the relationship ties between the donor and the recipient (89.66%). The result of this study provides the possible solution to strategize plan in enhancing awareness about organ donation.

Keywords—Attitudes, Barriers to Organ Donation, Donor, Recipients, Social Influences.

I. INTRODUCTION

Organ donation can mean the difference between life and death for millions individuals. It represent a better quality of life especially among those who are in need for special organ such as kidney. Organ donation, words that can be defined as taking the healthy organs and tissues from a dead, dying or living person and transplants it to another person [1]. It is often organ donation issues such as suffering of patients requiring organs donors to continue living been discussed in radio channels, television stations, printed Medias, and websites including social networking sites like Facebook and Twitter. This is because, organs such as corneas, kidneys and hearts are needed by people to live.

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The trend indicated that, there is an increasing number of patients who need these organs, while at the same time, the number of donors who come forward to donate is significantly become lower from year to years [2]. It is very sad to think that some of them are counting to the end of their days as the expected donor does not appear as expected. The patients come from various background of race, age and gender, who are suffering while waiting for generous donors to come forward to donate organs suitable for them. However, it is not easy to obtain a suitable donor as compared to donate money [3].

II. LITERATURE REVIEW

A. The Scenario of Organ Donation

Organ donation is one of the establish practice in the Western world but this practice is remains limited in developing countries. The most common organ donation is living organ donation where, it is widely practiced type in the world countries [4]. Prior studies have concluded that general factor that affects the willingness to donate organ is because of social and cultural differences in the Asian population compared to the West [5]. However, the major factors why this happens is because of the financial problem, expertise problem and donor availability problem [1].

Malaysia is one of the developing countries in that there is a huge difference of numbers between transplants that are being carried out and the needs of the population. Despite the fact that it has been over 30 years since the first organ transplant was carried out, the total number of transplants remains low for the current population of 28.31 [5]. In fact, Malaysia reported to have less than one donor for every one thousand of the population and among the lowest in the world [6]. Datuk Rosnah Abdul Rashid Shirlin, the former Deputy Health Minister expressed that, Malaysia currently has a total number of 12,133 waiting list patients who are in need of organ transplantation. 12,000 patients are suffering from end-stage kidney failure, 23 with liver failure and 10 patients with severe heart and lung failure problems [7]. Even that so, statistics from National Transplant Registry Malaysia confirmed a steady increase in number of registered potential donors each year and an increase number of donor in Malaysia. It is believed that, the shortage or organ donation is primarily caused by the failure and weakness of responsible bodies to identify the potential donors [7]. A very minimal

promotion, campaign and awareness programs are some of the reasons.

B. To be an Organ Donor

To become an organ donor in Malaysia, a person must declared him or herself as a Malaysian citizen and have given consent for donation of his or her organ and must have a donor card as proven by the registration status. The method of obtaining consent for donation in Malaysia is known as the 'opt-in method'. Though this method, a person will register him or herself with the National Donor Registry by stating their intention to donate organs when he or she is still alive. As an agreement, the donor will be issued with a donor card [5]. Contrary, as compared to 'opt-out' policy practice in Singapore, those who have died, hospitals will straight away remove the organs from the died body, unless there is an advanced formal objection to having organs from being removed when post mortem procedure taken place.

C. Barrier to Organ Donation in Malaysia

The shortage of organ donor is not only experienced by Malaysia. In fact, it is a global problem that is remains unsolved and the situation is becoming worse everyday. By understanding the reasons lying behind neglecting or refusing to donate organ, definitely will discover the barriers influencing people to donate their organs.

A barrier can be anything, either natural or manmade that keeps something from passing through. Generally, barriers to organ donation can be defined as something that prevents and influence people willingness to donate their organ. Prior research suggested that attitudes and social norms play an important role in deciding on donating organs [8].

D. Attitude as a Barrier

Attitudes can be defined as a positive or negative evaluation of people, objects, events, activities, or anything in the environment. It is a psychological tendency to express by evaluating a particular entity with some degree of favor or disfavor [9], [15]. The influence of one's attitude towards organ donation can be seen by a research conducted among Hispanic individuals in Arizona countries. A Spanish language mass media campaign that targeted organ donation in Arizona countries resulted in increase in pro-donation attitudes and family discussion one month after exposure to the campaign. The theme for the television advertisements was the efforts to save the life of potential donors by demonstrating the gift of life that organ donation can bring [10].

People in Malaysia act differently when discussing about organ donation. Donation is against one's belief, fear being "cut up" alive or having pain that lead to the death, organs donation violates one's sanctity, doctors' failure, mentally unprepared, against family wishes and fear of illegal organ donation purpose are some of the reasons that prohibited people in Malaysia to donate their organ.

E. Characteristics of the Recipients

A person's decision to involve in organ donation must be voluntary. No payment will be made for the donation and that is why, it should be considered carefully. Many studies have revealed that, people are willing to donate their organs to family members or close friends [11] without thinking of the payment. Rarely, people will involve in donation to somebody that they do not know.

Besides, different religious belief also may contribute to refusal of organ donation. Islam as for example, majority of Muslim scholar, both Sunni and Shia promote the importance of saving human life, based on teaching of prophet Muhammad who encourage his follower to seek possible medical treatment when they become ill [12]. This reflect the acceptance of organ donation as a treatment of a disease and for the sake of saving human life. However, the thoughts are varies because there is no unanimous support for the view because opinions are varied from one scholar to another [12].

F. Family Influences

Family members also play a critical role in promoting organ donation. Prior studies viewed that, one's attitude towards organ donation either it is positive or negative is shaped by their family members [11]. In fact, there is a study attempted to explore the causes of family refusal for organ donation. The reasons include denial and rejection of brain-death criteria, believing in a miracle, fear of organ trade, religious belief, unstable family mood and fear of objection from other family members [11], [13], [19].

Indeed, family members and relatives should be educated appropriately about organ donation in order to ensure the participation of potential donors. This is because relatives awareness and education about organ donation engaged and act as one of the modifier factors that influence the decision to donate organ [14].

G. Potential Risks and Complications

As a donor, an organ will not be simply take out from their body. The donor will need to undergo a medical evaluation in order to make sure that the donation will not pose any unusual risk to the recipient during the procedure or to future health. However, it is not surprise that some people are afraid of organ donation because fear of unexpected events including the risks and complications associated with organ donation and transplantation [8]. This may be not a problem for a dead donor, but, there are a number of risks associated with a living donor which include surgical complications, organ failure, scars, pain, fatigue, abdominal symptoms as well as increased risks with use of over the counter medications. Besides that, a living donor also may be expose to the potential psychosocial risks such as problem with body image, possibility of post surgery adjustment, possibility of recipient rejection and needs for re-transplantation, recipient with recurrent disease, possibility of recipients death and also the impact on the donor's lifestyle [15].

III. METHODOLOGY

This cross-sectional study is carried out in Alor Setar, Kedah with the total population of 217368 according to GeoNames geographical database 2012. Since a minimum sample size recommended is 30 [16], therefore, the researcher decided to conveniently select 120 respondents from three well known shopping malls in Alor Setar; Alor Star Mall, Mydin Mall and City Plaza. However, only 116 questionnaires were completed and returned. A set of close-ended questionnaire is developed which consist of three section; Section A: Demographic profile, Section B: Barriers of organ donation and Section C: Organ donation awareness. All questionnaires are distributed among the selected shopping malls visitors aged between 18 to 60 year-old. Data analysis is performed by using Statistical Package for Social Sciences (SPSS) version 20.0 through descriptive statistics and T-Test.

IV. FINDINGS AND DISCUSSIONS

A. Demographic Information

This research involved 116 respondents; 59 males and 57 females. 84 of them aged between 18 to 30, 24 of them aged between 31 to 40, 7 of them aged between 41 to 50, while only one person belongs to the last age group, 51 to 60 year-old. There were five ethnicity groups involved with 64 Malays, 21 Chinese, 18 Indians, 5 Sabahan and 8 Sarawakian. About 60 percent were students and single, while the rest are working as self-employed, private and government servants and un-employed. The summary of respondents' demographic information was presented in Table I below.

TABLE I
 DEMOGRAPHIC INFORMATION

| Respondents' Characteristic | n | |
|-----------------------------|----------------|----|
| Gender | Male | 59 |
| | Female | 57 |
| Age | 18-30 | 84 |
| | 31-40 | 24 |
| | 41-50 | 7 |
| | 51-60 | 1 |
| Race | Malay | 64 |
| | Chinese | 21 |
| | Indian | 18 |
| | Sabah Native | 5 |
| | Sarawak Native | 8 |
| Occupation | Student | 66 |
| | Self-employed | 9 |
| | Private | 12 |
| | Government | 17 |
| | Volunteer | 4 |
| | Housewife | 10 |
| | Retired | 1 |
| Marital Status | Single | 74 |
| | Married | 42 |

B. Awareness about Organ Donation

Consistent with number of prior studies [2], [5],[17], this study suggested that, all respondents were aware of organ donation and transplantation in Malaysia. Their source of blood donation news and information were mostly internet, television, newspaper/magazine, doctor and radio. However, as depicted in table Table II, majority of the respondents think that donating an organ is something that should be think of it twice. These people may be feared of organ donation. This is because, as one of the sources of organ donation information, the media not only spreading education elements to the public, but it also may contribute a significant public fears about organ donation [18] through the detriment of support for organ donation by representing a wide variety of organ donation issues. 91 respondents have a belief that organ donation will contribute a significant risk to their current health status and this may also be one of the reasons for refusal to donate organ among the population [17]. Only 13 of them would definitely want to donate organs irrespective of circumstances and 22 respondents would only like to donate organs under special circumstances.

TABLE II
 THE WILLINGNESS TO DONATE ORGAN

| | Frequency |
|--|-----------|
| Will never consider donating an organ | 11 |
| Will think about donating an organ | 70 |
| Will only like to donate under special circumstances | 22 |
| Will definitely want to donate | 13 |
| | 116 |

C. The Influence of Recipient's Characteristics towards Organ Donation

There were four possible recipient' characteristics that may contribute influence someone to donate their organ; relationship with the recipient, age of recipient, religion of recipient and health status of recipient. Table III showed the respondents' response where nearly 90 percent of respondents agreed the relationship ties between the donor and recipient play the most important role in organ donation. This can be supported by a study done by Irving, et.al.[11] where they found that one of the most influential themes that influence organ donation is relation ties between the donor and the recipient. Such thing happen because, people will always think of people closed to them first when come to the event of death [11]. Only 6 respondents agreed that religion of recipient will influence their decision to donate organ. The remaining 5 respondents choose health status of recipient and a respondent choose age of recipient.

TABLE III
 RECIPIENT CHARACTERISTICS THAT INFLUENCE ORGAN DONATION

| Recipient' Characteristics | Frequency | Percentage (%) |
|----------------------------|-----------|----------------|
| Relation with recipient | 104 | 89.7 |
| Religion of recipient | 6 | 5 |
| Health status of recipient | 5 | 4.3 |
| Age of recipient | 1 | 1 |
| | 116 | 100 |

D. Public Perception toward Organ Donation

This research also attempted to measure other barriers to organ donation, including the impact on health status as well as the possibly of donated organ been misused. Table IV indicated 91 respondents (male; 24.1% and female; 54.3%) perceived organ donation will bring a significant risk to their health status, while another 25 (male; 5.2% and female; 16.4%) respondents were uncertain. The perceived risks may include infections (30%), pain (20%), bleeding (19%), body weaknesses (16%), and anxiety as well as depression (14%). Based on the finding, it can be seen that, more female perceived negative views of organ donation compared to male. This is really true because female are more concerned about the transition of diseases through organ donation procedure [14]. The study also indicated that 5% of the respondents believed their organ will be misused after been taken out by the providers (Table V). The remaining 16% responded often, 66% respondent sometimes and another 12% did not believe on the misused of donated organ. This is really true especially in 'Black Market Sale' case. It is no longer a surprise that Malaysian think about the black market for organ transplants because there are many studies demonstrated that, people have a belief in a black market for transplants and it is widespread throughout the world [18]. This kind of sale is possible because one organ such as heart will has a value up to USD 1 million [15]. That is why, there is an effort by a special body such as United Network of Organ Sharing (UNOS) to monitor the distribution of organs. United State as example, declared that the human organ cannot be bought nor be sold in the Uniform Anatomical Gift Act of 1984. Even, the possibility of buying and selling of organs also is strictly prohibited by law in majority of develop countries.

TABLE IV
RISK TO HEALTH STATUS

| | Male | Female | Frequency |
|-----------|------------|------------|------------|
| Yes | 28 (24.1%) | 63 (54.3%) | 91 (78.4%) |
| Uncertain | 6 (5.2%) | 19 (16.4%) | 25 (21.6%) |
| No | 0 | 0 | 0 |
| | | | 116 |

TABLE V
FREQUENCY OF DONATED ORGAN MISUSED

| Frequency of Misused | Frequency | Percentage (%) |
|----------------------|-----------|----------------|
| Never | 14 | 12.1 |
| Sometimes | 77 | 66.4 |
| Often | 19 | 16.4 |
| All the time | 6 | 5.1 |
| | 116 | 100 |

IV. CONCLUSION

Human organs are the most valuable gifts of a human life. Thousands of lives have been saved and many more blessed with hope and happiness through a better quality of living because of organ transplantation. It may improve the quality of life of many patients on waiting lists and each posthumous donor can save an average of eight lives [19]. However, rapid development in transplant technology will be meaningless if the supply of the need in organs remains scarce and organ transplant procedures cannot taken placed accordingly. Therefore, this issue should be tackled carefully and continuous efforts in discovering the reasons of preventing people from being a donor is essential.

V. RECOMMENDATIONS

Based on the findings, it is to be recommended that, the responsible bodies, especially the Ministry of Health (MOH) should play their role in promoting organ donation in Malaysia. Not only through advertisement in electronic media and mass media, but also in all channels including online social medias such as facebook, e-mail and twitter as well as distributing flyers in the public areas. In fact, it is proved that, facebook as a social medium has contributed to a significant increase in organ donation registration [20]. It is such an effective tool of communication and education in this new era.

Furthermore, it is also important for health practitioners to conduct a public awareness seminar or talk to discuss about the current issue of organ donation. Organize a stand in shopping malls, cinema or other busy areas also may be a great promoting strategy to get the organ donation support from the public.

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