



**KNOWLEDGE AND ATTITUDE AMONG MALAYS IN
KUCHING, SARAWAK TOWARDS ORGAN DONATION**

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ABSTRACT

Organ donation and transplantation is becoming one of the alternative treatments for patient with organ failure. World widely, people are demanding for organ transplant as the result of good records of successful surgeries and greater survival rate among the recipients. Currently, the demand is exceeding the supply of organs with the long waiting list. Globally, people encounter the same obstacles in organ transplantation that is the shortage of organ donor, as well as Malaysia. This study is designed to determine the knowledge and attitude towards organ donation and factors that are prohibiting Malays (the largest race in Malaysia) from registering as organ donor nominator. A descriptive study is conducted to 60 Malay participants for Kuching, Sarawak. A self-administered questionnaire is used as the assessment tools for data collection. Questions assessing the level of knowledge and attitude of respondents towards organ donation and their religious view so on to determine the factors influencing their unwillingness to be a donor. The findings revealed that participants with higher knowledge possess more positive attitude. Factors like age, educational status and close exposure to person related to organ donation contribute to the participants' knowledge and attitude level. Religious-related factors are also among of the reason for the low organ donation rate among the Malays.

CHAPTER I

INTRODUCTION

Greater incidence of lifestyle-related diseases like kidney diseases, liver cirrhosis, lung diseases and heart disease nowadays have led to an increase in the incidence of organ failure. The Ministry of Health Malaysia has taken initiatives to manage this phenomenon through organ transplantation by developing a comprehensive National Transplantation Programme. Organ transplant have been one of the best alternatives treatment and give those who suffers from such diseases a new hope to survive.

World widely, people had accepted organ transplantation due to good record of successful surgeries and survival rate of the recipients. Now, the demand for organ transplantation is increasing. However, in Malaysia, transplantation activity remains relatively low as in 2005, there were only several transplant surgeries carried out which included 192 corneal transplants, 145 bloods and bone marrow transplants, 46 kidney transplants, 5 liver transplants, 1 heart and 1 lung transplant (Report of National Transplant Registry 2005, 2005). Out of 192 corneal transplants that carried out, only 12% of the corneal are from our local donor. The rest are from United State, and Sri Lanka.

Obviously, the demand and supply is not compatible. The demand is getting higher each day, but there are not enough donors especially from local donors. According to National Transplantation Registry in 2005, the cadaveric organ donation remained at the low level of 0.53 per million populations. There were 13 donors in 2005, five were brain dead multi-organ and tissues donor and eight were post cardiac death tissues donors. Out of those 13 donors, seven were Indian, five were Chinese and only one Malay donor. Statistic of organ donor according to ethnic group from 1997 to 2005 showed that only six donors are Malays compare to other races like Chinese (81) and Indian (43), and statistic of organ donor according to religious from 1997 to 2005 shows that only eight donors are Muslims while Buddhism is 46 and Hinduism is 36. According to National Transplant Resource Centre, Malays remain as the lowest rank race in organ donor nominator from 1997 till 2003 behind Chinese and Indian.

Even though, Malays is the largest population in Malaysia but only 5293 person had registered as an organ donor and this accounted for only 0.04% of the whole Malay population. In contrast, 47240 Chinese had registered as organ donor and representing 68.1% of the whole organ donor nominator and 0.8% of the whole Chinese population in Malaysia. The difference is very wide which has prompted the question; Why Malay does not register as an organ donor nominator?

Operational definition of terms

Organ donation – giving (no incentives is gain by donator or the eligible individual from the action such as monetary or other direct benefits from the receiver) an organ or organs to other individual or individuals who need a transplant via medical surgery.

Organ donor – an individual who donated his/her organ or has registered to donate his/her organ.

Attitude – a psychological tendency that is expressed by evaluating a particular entity (organ donation) with some degree of favour or disfavour with or without action or behaviour supporting it.

Knowledge – what is known, fact or information, awareness or familiarity in a particular field (organ donation)

Cadaveric donor – a brain-dead individual who had previously registered as an organ donor or with family members' permission of donating organ after his/her death.

Living donor – a living individual who is willingly donated his/her organ to another individual/individuals and the action will not harm the donor's life. (Donating the organ or organs will not cause death).

CHAPTER II

LITERATURE REVIEW

International and local development of organ donation

Organ donation and transplantation is one of the advance live-saving methods for patient who suffers from organ damage. It is well establish in most countries such as United States of America, United Kingdoms, Japan, France, New Zealand, Spain, Singapore and many other developed countries.

Port, Dykstra, Merian and Wolfe (2004) published a summary of the solid organ transplantation and donation in an article of Organ Donation and Transplantation Trends in 2003. According to the 2002 statistic, more than 24 000 organs was transplanted in 2002, 18 000 of the organs from the deceased donor and others are from the living donors. But, more than 6000 patients were reported to have died while in the waiting list. Similar to other countries, USA also suffers from the shortage of organ donor due to the increasing organ demand.

Port, Merian, Goodrich and Wolfe (2005) reported an increased transplantation pattern, 25 083 organ were transplanted in 2003 and 26 539 in 2004. Similarly the number of deceased and living donors also increased. Unfortunately, the number of patient who died in waiting list is also increasing.

World Health Organization organized a consultation meeting on transplantation with National Health Authorities in the Western Pacific Region in Manila, Philippine on 7-9 November 2005. 17 countries participated in the meeting and presented each country's current situation regarding organ donation and transplantation. The commonest problem faced by the countries is the shortage of organ to be transplanted. Lack of legal framework for organ transplant and donation also rise up as a problem faced by some countries like China.

Cornea, kidney, liver, heart, lungs and other organ transplantation has been perform and achieved good result in the recipients. The promotion and encouragement from the governmental and non-governmental organization facilitate in advertising organ donation to the society. According to Port et al. (2005), in US, there are more than 140 000 organ donor in 2004 with 26 500 transplantation surgery been performed. Out of those donors, 7 002 donors are living donors and others are deceased donors. This increase in donors had also given good impact in number of transplantation performed. However, the supply of organ still far behind the available organ as the demand had also increase. The numbers of patients on waiting list keep growing as more patients are added to the list than are removed due to transplantation, death or others. The figure of this report also demonstrated the increased public awareness as the number of living organ donor is also increase beside the deceased organ donor.

According to Delmonico, Sheehy, Marks, Baliga, McGowan, and Magee (2005), the donor trends in US is also influence by family members consent, religious belief, gender, race and ethnicity. Finding of this study shows that the minority groups in US such as African-American and Asian have recorded a lower donation rate compare to

the majority group. In contra, these minority groups do not show a lack of need for transplantation within these groups. Women are more likely donate their organ especially kidney, than men. In 2003, women constitute nearly 60% of the overall living donor. Lack of knowledge and misinterpretation of the donation and transplantation process and also mistrust towards the medical team are among the listed factors that lower the donation rate among the minority population in USA. Religious is also one of the reasons for affect the donation rates in those groups. Religious are important values that give a deep impact in a human life, so by understanding those important values, identifying the basis of the refusal or willingness of a person towards organ donation can make possible. This is essential in promoting and encouraging the society to participate in organ donation.

Many researches had been conducted internationally, exploring and studying not only the perception of various societies but also assessing and monitoring the development of organ donation and transplantation medical technologies. Those researches will not only enhances the participation of public in organ donation, more over, it will also boosts the development of medical field particularly in organ donation.

Miranda, Vilardell, and Grinyo conducted a research in 2003 studying the gap Spain society face between the demand and the supply for organ transplant. Various alternatives had been proposed in expanding the donation rate in Spain including living donation, non-heart-beating donors and also expanding the criteria for organ donor acceptance. Spain government had also establish a system to monitor the donation and transplantation activity in Spain including trained a network of medical professional that

act as transplant coordinator in hospital setting. Those alternatives had produced its great effect as the donation rate increase from 14 mil/ population to 34 mil/ population. Another study was conducted in 2003 by Jendrisek, Hruska, Wagner, Chadler and Kappel, trying to provide new option in deceased donor organ recovery while waiting for transplantation. Mid-America Transplant Service (MTS) was established to conduct deceased donor organ recovery outside hospital setting. Compare to conventional hospital-based recovery, MTS recovery had reported with significantly reduced critical care unit time, operating room delay, reduced organ cold ischemia and cost saving. MTS was equipped with one operating room (OR) and with the good result from the novel programme, it is now expended with the addition of one OR and a preoperative unit. MTS is also equipped with professional organ donation coordinator with certain range of experiences. This new method had given good impact in organ donation development.

However, organ donation and transplantation is still new in Malaysia. Even though the first transplantation activities started in 1970 with cornea transplantation followed by kidney in 1975, then bone marrow in 1987, heart in 1995, upper limb in 1997 and liver in 2000, but only on 1st November 1997 the National Transplant Resource Centre was established. In 2003, Malaysia Ministry of Health begin to put this matter as their concern and start to focus and promote organ donation. National Transplantation Registry was established and carried the responsibility to promote, manage and monitor organ transplants and donation in this country.

Currently, the National Transplant Resource Centre 1997-2003 statistic had recorded approximately 69369 organ donor nominator throughout the country. Sarawak, the

largest state in Malaysia takes the 11th rank out of the 16 states. Beside that, National Transplantation Registry had reported a total of 132 cadaveric organ donors in 1997-2005 donating various organ and tissues.

Malay as the target race

There are several researches had been done studying perception of different societies and groups of people towards organ donation include university students, medical and nursing students, Muslim society, medical staffs, donor's family, Italians and adolescents. From those studies, it had been proved that race and ethnicity is an important figure in determining their perception.

Spigner, Weaver, Ca'rdenas and Allen (2002) study on organ donation and transplantation: ethnic differences in knowledge and opinion among urban high school students. The purpose of the study is to assess the knowledge and opinion about the process of human organ donation and transplantation among American teenagers. A culturally sensitive 35-item of self-administered survey assessing knowledge, opinion and family discussion regarding organ donation and transplantation was distributed among 247 students from 3 urban high schools in the same city. The study reveals that there are significant differences in the willingness rate among the students according to their ethnic groups. African-American and Asian-American students are less likely to become an organ donor compare to the white-American. The knowledge about organ donation among those students is also poor as more than 50% of the students fail to answer correctly 13 out of 16 factual knowledge questions. The limitation of this study is the used of dichotomous race and ethnic categories that did not adequately represent precise grouping of the participants. Thus, affect the overall analysis of the study.

Baughn, Rodrigue and Cornell 2006, study was conducted to determine whether the adolescents with the expressed commitment of becoming organ donor registrants differs significantly from non-donor in term of socio-demographic characteristic and to assess factor that influence the intention of adolescent to register as organ donor. The finding of the study reported that only 49.2% of the 445 participants have intention to donate their organ. Out of that figure, 52.6% are female. The donation intentions are also lower among minority participant especially black and Hispanic compare to the white (55.8%). The figure is actually proportional with their overall population like Hispanic/Latino represents 13% of USA population and contributes about 13% of the donor. There is no significant different noted in donation intention across religious affiliation. Baughn *et al* also stated that health-related research had consistently shown that intention does not always followed by behavioural action. So, not all adolescent that stated their intention in this current study will proceed with their intention.

Siminoff, Burant and Ibrahim study in 2006 tried to identify the reason lower organ donation rate by African-American by examining the knowledge and attitude. It also reveal a significant different exist between ethnic group and their willingness to be a donor. African-American compare with white, are less likely to sign a donor card (39.1% vs. 64.9%), donate their (72.6% vs. 88.3%) or their loved ones' organ (80.9% vs. 93.1%). They are also have less trust in the health care system and more likely to favour benefits for organ donation. In term of knowledge, the African-American had also lower knowledge regarding brain death compared to the white-American.

Malaysia is a multiracial country constitutes of various different races with 3 majority races that are Malays, Chinese and Indian. Malays appeared as the largest population in Malaysia. According to Koh (2005) in Malaysia Statistic Department Report 2005, Malays constitute about 13 116 000 out of 25 991 400 (50.46%) in the first quarter of 2005 Malaysian population, followed by Chinese (25.3%) and Indian (7.54%). With this population, Malays should appear as the highest organ donor nominator in Malaysia but in contrast, Malays recorded as the lowest (4%) among the 3 largest races in Malaysia. Chinese appeared to be the leading race with 59% and Indian with 31%. It is a complete different from the finding of the studies as most of them shows that the minority ethnics or races presented with lower donation rates compared to the majority ethnics. But, obviously ethnics group or races played a crucial role in determining the willingness of donating organ.

The donor figure differences between male and female is also different from the literature finding that usually shows that female has more positive attitude towards donation and represent with more donor. But, in Malaysia, the male dominate the donor registry with 82% compare with only 18% are female donor. Moreover, according to 2nd Report of National Transplantation Registry 2005, Malays are among the highest organ recipients of most of the donated organ especially heart valve (61.3%), heart and lung (31.3%) and bone marrow (37%) despite of their lowest donation rates. So, the demand and supply of organs are not balance especially in Malay community. With this imbalance figure, it is essential to study the factors forbidding Malays from donating their organ so that, interventions can be applied to promote and increase the registered organ donor among Malays.

Knowledge and source of information

Spigner et al. (2002) reported the finding of the study that the participant's knowledge level on organ donation is relatively low. More than 50% of the participants (247) answered wrongly in 13 of 16 factual knowledge questions. The knowledge about transplant is also relatively low. The finding demonstrates the students' lack of accurate information about donation and transplant. More 'don't know' answer indicating the need of more accurate information. This finding is proportional with the donation intention rate among the participants in this study. The donation rate is low as the knowledge level of participants is also low. So, knowledge does influence the intention of a person to donate his organ.

Assessment of knowledge is essential to identify if the Malays have adequate and correct information about organ donation and transplant. Is it due to their lower educational background or lack of information about organ donation that make them reluctant to registered as organ donors.

Family members consent is also plays important role in donating organ. Family members are the one to give consent for organ donation if the patient is unable to do so. Enough information and family discussion is important beforehand and will help the family member to make decision. Rodrigue, Cornell and Howard (2006) study on organ donation decision: comparison of donor and non-donor families reveals that family members with adequate information about organ donation are more likely to give their consent for donation. 70.5% of next-of-kin who had complete knowledge about brain death agree for donation. The donation rate is also higher when a brain death explanation was provided (74.4%). Moreover, since the donation request usually occurs

within the context of intense grief and despair, knowledge of the deceased's intentions helps to reduce ambiguity and conflict among family members and to lessen the saliency or interference of other variables in the decision-making process. Not only the donors' knowledge is important, but the next-of-kin as well.

Barcellous, Araujo and da Costa (2005) study on organ donation: a population based study aim to identify the prevalence of people willingness to donate their organ and from their relatives. This cross sectional study targeted people above 20 years old in Pelotas, Brazil. The result shows that from 3159 participants, 52% of them are willing to donate their organ and 80.1% will consent for their family member's donation. This study also reveals that educational background and income influence the willingness for donation. The donation rate increase along with the years of education. 68.8% of participants with more than 12 years of education declare their willingness compared to only 36.6% of illiterate participants that willing for donation. Barcellous *et al* also concluded that sociodemographic characteristic influence the rate of public willingness to donate organ.

Gross, Martinoli, Spagnoli, Badia and Malacrida (2001) on the study of young European attitude and behaviour towards organ donation had found out that level of information is one of the factors influencing the decision to donate organ. 1142 participants from Swiss-Italian recruited army were assessed on their level of knowledge. Only 224 (19.6%) of the participants feels themselves to be sufficiently informed. Out of those figure, 73.7% of them are willing to donate their organ compare to only 61.5% of participants who feel insufficiently informed. Form the above figure, the study showed that the level of information among the concern society is alarming

and lots of educational campaign had end up in disappointment. New approaches and implementation are needed in improving public knowledge on organ donation thus enhancing public intention to donate organ.

Gross et al. (2001) also compare the willingness to donation with the educational level so examine if there any significant relation between them. 1088 participants were selected for this assessment. Educational level is divided into 3 different groups that are low, medium and high school level. 33.5% of the participants are in high school level while 20% in middle school and 57.9% in low school level. Within the group itself, the participants were asked on their willingness for donation. 71.4% of the high school level group participants stated their willingness for donation. 62.8% from the medium level and only 57.9% of the low school level participants willing to donate. Those figures show a significant relation between the educational level and the willingness for donation as the willingness for donation increase along with educational level.

First exposure to organ donation and transplant is also another factor that influences a person decision to be an organ donor. Mass media plays the most crucial role as it had a very huge influence on the community. The way media portray an issue will leave a deep impact on the viewers. Even though direct contact with a person who directly involve in organ donation or transplant is more influential, but there is not many people that encounter such situation.

Morgan, Harrison, Long, Afifi, Stephenson and Reichert (2005) research reveals that mass media acted as most influential information delivering system. Unfortunately, the media portrayed organ donation as negative and sensationalistic. Media had created

several myths that the viewer believed is true. The misconception portrayed by media had given a big impact on donation rate. Incorrect information provided by media had become an obstacle in improving organ donation rate. The society becomes less knowledgeable regarding the reality of organ donation as they are provided with the misconception of organ donation. Media, in the other hand, should operate as the medium to provide correct information about organ donation and enhance the society's knowledge regarding organ donation.

Spigner et al. (2002) stated that in addition to the need for better information, it is interesting that television ranked as the number one source of information for all students. Television might be influencing students' knowledge and thus shaping their opinions with misinformation. We can only speculate that students' responses could have been indirectly or subconsciously influenced through the viewing of such programming.

Attitude and its influencing factors

According to Dato' Dr. Noorimi in Consultation Meeting on Transplantation with National Health Authorities in the Western Pacific Region 2005, there are several remaining issues to be solve such as a national transplantation policy and a comprehensive transplant act need to be develop and establishing national transplant programme and activities to support and promote organ donation. Again, she said, the biggest challenge in Malaysia is that public perception and acceptance of transplantation is based on taboos or religious belief, family consent, accessibility to transplant centre and availability of ICU beds.

Attitude toward organ donation varied in each culture, religious, educational background, gender, age group, socioeconomic status and previous exposure of organ donation and transplant include mass media or direct contact with organ donor or recipient. Family members also play important roles to give consent for organ donation. Siminoff et al. (2006) aim to identify the reason for lower donation rate by African-American by examining the knowledge and attitude about brain death, donation, transplantation and trust in health care system. The findings presented that African American has less enthusiasm to become a donor and present with negative attitude towards organ donation compare to white. These include the unwillingness to sign as a donor or refuse to consent for family members who is eligible to donate. This group had also express greater concern on trustworthiness of health care system beside other influencing factor like religiosity, age and educational status. Baughn et al. (2006) also reported that the minority group like Hispanic and black are less enthusiastic towards organ donation than the white (55.8%).

Socioeconomic status will also determine the willingness to become a donor. Person with higher socioeconomic status tend to be more enthusiastic about donation compare to he lower socioeconomic status person. Barcellous et al. (2005) in their study said that subgroups of demographic and socioeconomic variables that presented higher prevalence of willingness to organ donation, in the multivariate analysis, were the younger, those of higher education and monthly household income superior to 10 minimum wages. Subgroup with lower educational background and low socioeconomic level had recorded to have less willingness to donate. The willingness for donation is higher (69.8%) in participant with household income that is more than 10 minimum wages. The willingness decrease as the household income getting lower, only 41.2% of