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Barriers to Organ Donation: The Application of the Theory of Planned Behaviour

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Abstract: Recent advances in the fields of organ donation and organ transplant have presented new hope for the treatment of serious diseases. However, this promise has been accompanied by several issues. Previous research on organ donation has suggested that, although most people are aware of organ donation, many are unwilling or has no intention to consider donating organs. The present study investigate the significant application of the Theory of Planned Behaviour (TPB) in predicting the intention to donate organs. The relationship between the variables: Subjective Norms (SN), Attitude Toward Behaviour (ATB) and Perceived Behavioural Control (PBC) and the key component of the theory, intention is examined. This cross sectional study has adapted questionnaire from previous research on the application of TPB. The study findings indicate that, all the three factors have significant strong relationship with the intention to donate organ. The greatest barrier to be an organ donor is Subjective Norms (SN). It is hoped that the result from this research may benefit both healthcare providers and patients in a multicultural society like Malaysia.

Key words: Intention, organ donation, Theory of Planned Behaviour (TPB), relationship, ATB

INTRODUCTION

Organ donation is a noble act that can save the lives of others. Organ donation have given hopes and lives to thousands of health impaired and terminally ill people resulting in better quality of life. Organ donation can be seen as one of the noble and effective methods that brings new hope to the patient in ensuring the survival of their lives. It has become a worldwide practice. Unfortunately, over recent years the waiting list for organ donation in Malaysia grows longer and longer each day." As of May 2012, Malaysia has 15, 399 patients awaiting organ transplants, with kidney patients topping the list. The similar situation also happens in United Kingdom, the long number of patients in the waiting list still unsolved since the numbers of people needing transplant are increasing by 8% every year.

In Malaysia, the first organ transplantation was carried out in December 1975 and it was a kidney transplantation. in which recipient who received a kidney from his brother had survived for thirty years before succumbing a major infection. Since then, Malaysia has undergone heart, liver and lung transplantation. Moreover, Malaysia also has recorded successful transplant surgeries for some tissues such as bone and bone marrow. The statistics shows that the awareness and intention to organ donation in Asian country are still lacking but it seems different with black market rate. The black market is emphasize on the monetary donor compensation which in unethically to practice. Based on Jingwei, organ transplant in Asian country was always be related with policy issue rather than clinical aspect. However without donor compensation, many countries including high income country facing same problem with low number of organ donor.

On the other hand, certain country has been implementing the Opt-out system in order to increase the number of organ donation. This would mean that family members never decline the right of each member in the family to donate the organ and the hospital can simply take the organ of the deceased individual during the post-mortem process without getting the permission from their family. Nevertheless, in order to solve the organ donations issue, the policy maker should understand the believe, culture and any other factors that can be influence the intention to donate organ. Therefore, the main objective of this study is to investigate the intention to donate organs and individual factors influencing organ donation using the Theory of Planned Behaviour (TPB).

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Literature review

Scenario of organ donation in Malaysia: The number of registered donors and people who are waiting for organs are increasing every year. However, both still cannot accommodate each other as the number of donors still less than the people in need. According to Datuk Dr Jeyaindran Sinnadurai, the Deputy Director of Health Ministry, until January 2015, the total number of people waiting for organ are 19, 353. Most of them are suffering from kidney failure and the number is expected to increase because of uncontrolled diabetes and hypertension complications.

Malaysia is among the countries with the lowest amount of organ donation with only 0.68% for every 1 million population, compared to Thailand, 1.28%, Singapore 5, Saudi Arabia 2.7, America 25.5 and Spain 34.4%. The statistic also indicates the number of organ and tissue donor is only 507 until 31 January 2015. Surprisingly, break down by races showed uneven as 59% are Chinese, 27 % are Indian, 6 % are Malays and the remaining 8 %are from other races though Malays are the majority group in Malaysia.

What is organ donation? Organ donation is where a person, living or deceased donates their organs or tissues for transplant. It happens when someone allowing their organs or tissues to be removed and given to someone else. Malaysian citizens who have the intention to donate an organ are required to fulfill certain identified criteria before they are allowed to do so. However, the most important thing is by giving their consent for donation by registration status with the National Donor Registry. However, not everybody with the status of 'Malaysian citizen' can be a donor. Those with certain medical conditions such as HIV, actively spreading brain cancer and severe infections are restricted or recommended to not to donate their organs.

Barriers to organ donation: The shortage of organ donors has led researchers to study the real barriers of the problem. A study done by (Silva and Frontera, 2015) revealed that lack of standardization of organ donation criteria has contributes to reducing number of potential donors or in other words, brought a significant barriers to be an organ donor. The criteria may include disparity in legislation, racial, ethnic, religious and insufficient knowledge about organ donation. Those who belief that organ donation is not encourage within their religion will tend to reject the donation. The same also goes to people with lack of organ donation knowledge and awareness (Irving *et al*., 2012).

In addition, family also plays important role in determining the successfulness of organ donation because in some views, organ donation intention is always shaped by family members where permission should be granted first. At times, family may be a supporter but there are times when family can be a barrier to one's intention. This is because family members especially from the areas of insufficient education and resource utilization more often decline consent for organ donation of their immediate family members (Irving *et al*., 2012).

The Theory of Planned Behaviour (TPB): Theory of Planned Behaviour (TPB) was first known as the theory of reasoned behaviour. It has been formulated after Ajzen and Fishbein, the founders of the theory trying to estimate the discrepancy between attitude and behaviour in which it was related to voluntary behaviour. However, behaviour appeared not to be all voluntary and under control and as a result, they have added perceived behavioural control as another variable to the framework. Then, the theory is called the Theory of Planned Behavior (TPB) (Ajzen, 1991a, b).

The TPB emphasized that human behaviours are governed by personal attitudes, social pressures and a sense of control. According to the theory, in order to help predict future behaviour, the intention can devoid unforeseen circumstances that will limit individual control (Carmack and Moss, 2009). The key component of TPB is behavioural intention. This key component is proved to be influenced by someone's Attitude Toward Behaviour (ATB), Subjective Norm (SN) and Perceived Behavioural Control (PBC) (Ajzen, 1991a, b). Attitudes toward behaviour is where the intention is influenced by the attitude of the person, subjective norm refers to a person's belief about how people view about the behaviour and perceived behavioural control explained the perceived ability or individual perception of their ability to carry perform the action.

The key general rule explained by Ajzen is more desirable and the greater Attitude Toward Behaviour (ATB), Subjective Norm (SN) and Perceived Behavioural Control (PBC), the stronger the intention to engage in a behaviour in question. To date, TPB has been widely used to predict and explain a wide range of health behaviours and intentions including smoking, drinking, health services utilization, breastfeeding and substance use (Glanz *et al*., 2002).

The Theory of Planned Behaviour (TPB) and organ donation: The present study aims to investigate the barriers of organ donation through the application of the Theory of Planned Behavior. Review of literature showed that, many studies have completed the assessment of one's intention toward organ donation by using the TPB. All have shown the predictive success of required behaviour tested not only toward organ donation but also

blood donation, halal food purchasing, the usage of technology among students and teachers, condom used and many more (Carmark and Moss, 2009; Natan and Gorkov, 2010). For instance, a study by Masser *et al.* (2009) found that, the TPB has proved efficacious to predict the intention to donate blood. The study emphasizes the importance of considering the intention of an individual to predict the motivation of the future behaviour.

A few years later, a study among student by (Rocheleau, 2013) demonstrated the consistent findings where the three components in TPB are shown to be associated with the intention to donate organs. Attitude toward behavior (Breitkopf, 2006), subjective norm (Morgan, 2004) and perceived behavioral control (Brug *et al*., 2000) are identified as successful predictors of organ donation related decision in specific setting. This supports the use of TPB in predicting the donation-related intentions and suggests potential targets from the population for future reference.

Among the three components, a person's attitude or ATB is shown to be the major determinant or in other words, barrier of one's intention (Rocheleau, 2013; Samart, 2008) in most research study, where the attitude is influenced by both positive and negative perceptions on one's attitude. This may include belief hold by someone about a behavior to perform. A good example to support this statement is studies done by Powpaka in which he found that attitude toward behavior is the most reliable factor of individual intention to donate organ. This clarifies that the more an individual values a behaviour, the more likely they are performing the behaviour.

In some other research findings, perceived behavior control has also shown a significant predictor of organ donation (Brug *et al*., 2000). This suggested that, individual perception about the level of difficulty associated with organ donation will influence individual intention to donate organ later.

MATERIALS AND METHODS

A cross-sectional study was carried out in the community of the capital city of the state of Selangor. The survey was conducted in several designated areas; including shopping malls, restaurants, several bus stops and recreational parks. Respondents were assisted in completing the questionnaire.

A survey questionnaire was used and adapted from established questionnaires in previous studies (Ajzen, 1991a, b). This questionnaire consists of three sections which include Section A, B and Section C. A Likert type scale was used to measure feedback from respondents. In Section A, there were nine items focused on the demographic information of the respondents. The questions in this section are basically concerned about the background of details of respondents such as gender, age, education background, marital status and religion. This section also consists of items which getting response from the respondents on whether they have been registered as the organ donor or else. In Section B, there were 21 items which have been divided into three parts including subjective norms, attitude towards behaviour and perceived behavioural control of respondents. Finally, there were three items in Section C concerning on intention to donate organs. Overall, the survey question has four sections with 33 items.

A total of 449 questionnaire was completed and valid for data analysis purposes. Both descriptive and inferential statistical analyses were employed in this present research study. The descriptive statistics included mean, frequency and standard deviations. Bivariate analysis was also used to investigate the relationship between the variables in this present study. Data obtained was analyzed using the IBM Statistical Package for Social Science Software (SPSS) Version 22.0.

RESULTS AND DISCUSSION

Data findings of the present study are described and discussed in the following study.

Descriptive analysis: The demographic profile of the respondents includes gender, age, race, marital status, educational background, religion and the organ donation option. Data findings of the demographic profile and background are described in Table 1. The study findings showed that more than half of the respondents were female (62.4%, n = 280) and 37.6% (n = 169) were male. Approximately half of the respondents (45.9%, n = 206) were aged between 18-29 year old and nearly 30% (n = 131) were aged 30-49 year old. Meanwhile, 20% (n = 90) of the respondents were in the range 50-65 year old. Less than 5% of the respondents were above aged 65 (22%). The majority of the respondents were married (70.6%, n = 137) while 26% of the respondents were single (n = 51) and only 3.1% (n = 6) were 'other status'. Most of the respondents were Malay (89.1%, n = 400), followed by the Indian community (5.3%, n = 24), Chinese (4.2%, n = 19) and only 1.3% (n = 6) were from other races. In terms of academic background, 71% of respondents were Diploma/Certificate and Bachelor's Degree holders (36.5%, n = 164; 35.5%, n = 155, respectively). Twenty-six percent (n = 116) obtained an SPM / STPM certificate. Only 3% (n = 14) of the respondents had a Master Degree

Table 1: Demographic profiles (N = 449)

Variables	n	Percentage
Gender		
Male	169	37.6
Female	280	62.4
Age		
18-29	206	45.4
30-49	131	29.2
50-65	90	20.0
Above 65	22	4.9
Race		
Malay	400	89.1
Chinese	19	4.2
Indian	24	5.3
others	6	1.3
Maritial statue		
Single	214	47.7
Married	218	48.6
Others	17	3.7
SPM/STPM	116	25.8
Education level		
Diploma certificate	164	36.5
Bachelor's degree	155	34.5
Master's degree	14	3.1
Religion		
Christianity	9	2.0
Buddhism	9	2.0
Hinduism	22	4.9
Registered organ doner		
Yes	66	14.7
No	383	85.3

Table 2: Correlation coefficients of variables

Variables	Mean	SD	1	2	3	4
Subjective norm	3.05	0.79	1.00			
Attitudes	3.78	0.67	0.474*			
Perceived of Behavioural control	3.78	0.68	0.423*	0.757*		
Intention to donate	3.12	1.05	0.575*	0.639*	0.576*	1.00

*Correlation is significant at the 0.01 level (2-tailed)

qualification. Based on the Table 1 also, 85% (n = 383) respondents were not a registered organ donor and only 15% (n = 66) were a registered organ donor.

Summary of mean and standard deviation of the variables is presented in Table 2. Respondents rated their subjective norms, attitudes and perceived of behavior control. These constructs were measured using the five-point Likert scale format ranging from totally disagree to totally agree. Most of the means score for each item were below the scale of 4.00. All the standard deviation values were in narrow ranges. However, respondents rated their agreement in the statements as uncertain for several items. The statements were shown in the Table 2. All items of intention to donate organs were rated as uncertain.

Among the three individual factors, subjective norm is seen to be having the lowest means score. Subjective norms is one's belief of the perceptions of others towards their action, it can be assumed that most of the respondents are merely concerned about what their family perceived when they pledged as a donor. Family members had contributed 40-50% of their deny consent for the donation intention of their kin's organs and it also lead to lack of consent . Meanwhile, most of them indicated their possession of control over their decisions on pledging as a donor. Thus, it can be said that control over own decision is not a problem but control over the decision of one's loved one over their own decision to pledge as a donor is in question.

Perceived behavioural control can be described as the perceived ability of one to perform an action. As indicated earlier, most of the respondents agreed that they were aware of the benefits of organ donation and they were willing to pledge as a donor. The finding is consistent with the study conducted by (Natan and Gorkov, 2010) where they found that perceived behavioural control influence the students' intention to donate blood. It is assumed, when they have the believe that they want to do it and they can do it. This actually reflects their understanding and knowledge of such good deed. This also can be reflected looking through the most positively rated factor that is the attitude. The finding revealed attitude as the most significant predictor of intentions to donate organ among others which is consistent with most prior research. However, looking through the result generated through this study, it can be concluded that the respondents were mostly uncertain about their intention to engage in organ donation.

Correlation analysis: A bivariate analysis was conducted to examine the relationship between intention to donate organs and individual factors including subjective norms, attitudes and perceived of behavioural control. The data findings found that intention to donate organs correlates strongly and positively with the individual factors; in which include subjective norms ($r = 0.58$, $p<0.01$), attitudes ($r = 0.64$, $p<0.01$) and perceived of behaviour control ($r = 0.58$, $p<0.01$). This is supported by Carmack and Moss (2009), Natan and Gorkov (2010) and Rocheleau (2013).

where the studies found that, the three factors influence one's intention towards a behavior. Table 3 describes the correlation analysis using the Pearson product-moment correlation technique. It thus can be explained that the level of organ donation intention will increase when the level of subjective norms, attitudes and perceived of behaviour control in individuals are increased. However, the present study findings showed that respondents were uncertain to the subjective norms ($M = 3.05$, $SD = 0.79$) and intention to donate organs ($M = 3.12$, $SD = 1.05$).

Table 3: Summary of means and standard deviations of the variables (N = 449)

Item	M	SD
Subjective norms		
Most people who are important to me think I should be an organ donor	2.95	1.04
My family encourages me to donate an organ	2.73	1.02
Most people who are important to me would approve me registering my consent to donate my organs upon my death	2.91	0.98
I have a complete control over whether I discuss my organ donation decision with my partner or family members	3.60	1.07
Attitudes		
I know organ donation can help many people	4.31	0.78
If I am pledging to become the organ donor, I know it will not affect my health	3.64	1.03
I believe that the public should be exposed to awareness to become an organ donor	4.10	0.82
It is important for everyone to pledge as a donor	3.49	1.00
I am very concerned about the increasing numbers of people who are waiting to receive the organs	3.81	0.88
I am really concerned about my decision to become an organ donor can affect others life	3.66	0.91
I always know and concern of the danger that are waiting for too long for the organ transplant	3.82	0.86
Telling public to become a donor is crucial	3.90	0.91
Doctor has big influences in my attitude towards organ donation	3.61	1.00
I am willing to donate organs if one of my next kin has a bad past experience in organ donation	3.48	1.06
I believe that my act becomes an organ donor will reduce the number of people in the waiting list	3.81	0.96
Perceived of behaviour control		
I have a good knowledge about organ donation/ transplant in general	3.24	0.96
I support the idea of organ donation for transplant purposes	3.76	0.87
I believe that organ donation is an act of compassion	3.64	0.96
I view organ donation as a benefit to humanity	4.00	0.82
I think that doctors would try just as hard as possible to save my life, whether or not I plan to be an organ donor	3.90	0.87
In general, I think that organ donation is a good act	4.16	0.81
Intention to donate		
I am intending in organ donation and willing to donate	3.19	1.04
I plan to become an organ donor after my death	3.16	1.10
I will donate my organ to a stranger who needs it	3.00	1.22

CONCLUSION

In conclusion, organ donation awareness may still considered low among adults in Malaysia. It is important to increase the awareness on organ donation and focus more on educating the public to support the family member's decision to become a donor. The findings of this study are very crucial especially for the government or policy maker to formulate interventions to increase the total number of organ donors. It is recommended that the future research should engage a bigger sample so that the finding can be generalized into the bigger population. Moreover, the inclusion of culture dimension should be considered for future research as one of the factors that may affect one's intention to donate organ.

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