

Youth Acceptance towards Organ Donation Policy in Malaysia

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Abstract - Over the past decades, several important policies have been set forth in Malaysia in order to facilitate organ donation. However, these efforts have brought little effect and significant changes in the situation of organ donations in Malaysia. This situation results in an urgent need for sound policies in order to elevate the donation rate. Generally, there are two types of legislations for obtaining consents for organ transplantation namely informed consent (IC) and presumed consent (PC). This paper attempts to identify youth acceptance in both IC and PC based on their demographic factors. The questionnaires were distributed to 800 youths aged between 15 to 40 years old who are living in the Klang Valley. However, only 622 questionnaires were usable for further analysis. This paper is vital as it helps the government to measure the readiness of Malaysian youths to accept a new policy (presumed consent) of organ donation as a means to increase the donation rate.

Keywords - informed consent, organ donation, presumed consent, youth acceptance

I. INTRODUCTION

Generally, there are two types of policies for obtaining consent for organ transplantation which are informed consent (IC) and presumed consent (PC). The informed consent policy, commonly known as the “expressed consent” or “opting in” system, states that citizens who wish to become an organ donor have to voluntarily register as organ donors [1]. Meanwhile, the presumed consent policy is also known as the “opting out” system mentioned that citizens are automatically registered as deceased donors unless they fill up a form declaring their refusal to become a donor [1]. Reference [18] contend that Malaysia is one of the countries that applies the IC policy which resulted to severe organ shortage.

In April 2012, there were only 194,846 out of 28 million people signed up as organ donors in Malaysia. In other words, only 0.66 percent donors per million populations which is lower than other countries that utilize the presumed consent (PC) system such as Spain (34.13), Belgium (25.61), France (25.31), and Austria (20.72) [18]. This system has been extensively used in many countries because it results in higher donation rates rather than the IC policy [1]. Therefore, the organ shortage problem in Malaysia is believed to be addressed by replacing the IC policy with the PC policy.

In order for Malaysia to implement the PC policy in the future, some efforts, especially in educating the youths, are required. It is important to gauge the youth acceptance toward this policy because they are the donors of the future and also the future leaders of the country. It is vital to reach them because they are the ones who could provide a lifesaving organ in years to come. They will also play an important role in raising awareness for the public in the future about the value of donation in life and after death as well as in encouraging them to think about becoming donors themselves. This is supported by a statistic from the National Transplant Resource Centre (NTRC) which shows that the highest number of people who pledged for organ donations are from the aged between 21 to 30 years old which is about 78,906 or 38.06 per cent.

II. RESEARCH OBJECTIVES

1. To describe the attitude of youths with regard to the current policy (informed consent) based on demographic factors.
2. To describe the attitude of youths with regard to the proposed policy (presumed consent) of organ donation based on demographic factors.
3. To identify youths’ decision whether to sign out as non-donors under the PC system based on demographic factors.

III. LITERATURE REVIEW

A. *Presumed Consent Policy Practices in Various Countries*

There are several countries that have successfully implemented the presumed consent approach of organ donation.

1) *Spain*

Spain has the highest donation rate of deceased donors which is about 34-35 million per population. In 1979, Spain introduced a presumed consent policy which can be described as an opting out system [6]. At first, the donation rate in Spain was only 14 per million; however, a drastic increase of donation rate was noticed right after the establishment of the National Transplant Organization in 1989. It was known as a new infrastructure that led to a lot of improvements by providing a lot of trainings and

supports to all the coordinators that are involved in the transplantation process [15]. There was a positive implication to the donation rate as it increased steadily from year to year where in 1997, it increased to 29 donors (pmp), followed by 1998 with about 30 donors (pmp) and, recently in 2007, it reached 34.4 donors (pmp) [20]. The other factor that led to the successful implementation of PC in Spain was that it applied a soft approach where the families' views were considered and allowed them to refuse the donation even if the deceased wanted to donate his/her organs [14]. Besides that, Spain also prohibits any advertising for organ or tissue donation from individuals or health centres because it still emphasizes that organ donations should be based on voluntary values and the spirit of altruism [20].

2) Belgium

Belgium has the second highest donation rate right after Spain which is about 25-26 million per population. Belgium has adopted the PC system for more than 10 years. In Belgium, the people may exercise their right to opt out of organ donation by filing out an objection at any local town hall where a computerised system accessible only to transplant officials was kept [8]. However, doctors are still encouraged to discuss organ and tissue removal with the deceased's relatives. In addition, the changes to the system resulted in the number of kidney retrievals increasing from 18.9 (pmp) per year to 41.3 (pmp) per year in only 3 years. However, in Belgium, the use of living donors for transplantation is not permitted except for cases where comparable results cannot be obtained with cadaveric organs. Specifically, the use of living unrelated donors is thus unlawful, although one centre is still doing it and there is no legal action taken from the authorities. Belgian transplant coordinators must check the registry and print out the related medical records before starting the organ retrieval process. This illustrates the benefits of the PC system as compared to the IC system, where the will of the deceased is often unknown and, even when expressed on a signed donor card, can be overridden by the relatives [10].

3) Austria

Austria is among the countries that has a better rate of organ donation which is about 20-21 million per population. Austria applies a hard approach of the PC policy whereby the views of the relatives are not considered and the process relies solely on the individual's decisions for the transplantation process. Thus, organ transplantation proceeds unless there is an objection by the deceased before death. This system has enabled Austria to claim the highest cadaver kidney donor rate among the leading transplant countries where the country was able to increase more than double their donation rate of 4.6 per million people per year (pmp/yr) to 10.1 pmp/yr in 1985, after four years of implementing the hard opting-out system. Today, Austria continues to have an impressive donation rate [16].

B. Previous empirical studies related to PC policy of organ donation

Previous researchers [1-3, 5, 7, 9, 11-13, 17, 19] had employed studies on matter pertaining to PC policy of organ donation and its effectiveness in elevating organ donation rate. Generally, the findings of their studies found that PC policy of organ donation is able to elevate the rate of organ donation. In order to ensure that PC does not violate the rights of the people is to be sure that everyone acknowledges the system so that they can decide whether or not they want to become a donor when they are still alive. The implementation of PC will also be more effective with a good infrastructure that eases the process of signing out for everyone. In addition, public education and communication are also vital in order to increase the public's level of knowledge and understanding of organ donation.

IV. RESEARCH METHODOLOGY

To recap, this study attempts to identify youth acceptance level on IC and PC of organ donation. 800 questionnaires had been distributed to youths aged between 15 to 40 years old located in the Klang Valley area. The area is divided into three parts which are public institutions of higher education, including the National University (UKM), University Putra Malaysia (UPM), University Malaya (UM) and a few other private colleges, hospitals and also shopping malls. The population of this study is 800 youths in the Klang Valley and the sample size is 622 youths. This study employed convenient sampling technique and the questionnaires were utilized in order to get data from the respondents. All the data that had been collected in this study had been analyzed by using Statistical Software Tool SPSS Version 17 and descriptive statistics analysis.

V. FINDINGS

The findings of the study are categorized based on three research objectives. The first objective of the study is to describe the attitude of the youths with regard to the current policy (informed consent) based on demographic factors. The second research objective is to describe the attitude of the youths with regard to the proposed policy (presumed consent) of organ donation based on demographic factors. The third research objective is to identify the youths' decision whether to sign out as non-donors under the PC system based on demographic factors.

A. Youth attitudes towards informed consent of organ donation

In this section, there were three questions measuring youth attitudes towards informed consent of organ donation. Six levels of Likert Scale were employed namely strongly disagree, disagree, slightly disagree, slightly agree, agree and strongly agree. Mean of each item was utilized as the indicators to examine the attitude of youth under IC. Demographic factors such as ethnic, age and gender acted as independent variables of this study and the attitude

towards informed consent of organ donation represents dependent variable of this study.

Table I depicts youths' attitudes towards informed consent of organ donation based on ethnic, age and gender. The first question asked about youth's opinion whether it is convenient to register as an organ donor. Based on the Mean result, in terms of ethnicity, Indians are slightly higher than Malays and Chinese (M=4.1395) perceived ease of registering as a donor organ. Meanwhile, female youths aged below than 25 are more perceived ease of registering as a donor organ.

Second question asked about youths' confidence level on medical team to save their life first before transplantation process begins. In terms of ethnicity, Indians are slightly higher than other races (M=4.7674) have a confident on medical team to save their life first before transplantation process begins. Other than that, female youths aged more than 26 years old are more confident towards medical team in saving the life of youth before transplantation process begins.

Third question asked about youths believe that their family will allow the medical team to extract their organ for transplantation after they passed away in the event that they already registered to donate organ. In terms of ethnicity, the Chinese are higher than other races (M=4.2229) believed that their family will allow the medical team to extract their organ for transplantation. In addition, male youths aged more than 26 years old believed more that their family will allow the medical team to extract their organ for transplantation. Based on the three questions, it can be concluded that youths have a positive attitude towards informed consent as most of the Mean represent more than 4.

TABLE I. YOUTH ATTITUDES TOWARDS INFORMED CONSENT OF ORGAN DONATION BASED ON ETHNIC, AGE AND GENDER

Statement	Variables		N	Mean
Question 1 "I agree that it is convenient to register to become an organ donor in this country"	Ethnic	Malay	413	4.0630
		Chinese	166	4.0000
		Indian	43	4.1395
	Age	Below 25	480	4.0562
		26-40	142	4.0352
	Gender	Male	307	4.0326
		Female	315	4.0698
Statement	Variables		N	Mean
Question 2 I am sure the medical team will try their best to save my life first before they think of extracting my organ for transplantation purpose	Ethnic	Malay	413	4.7191
		Chinese	166	4.6687
		Indian	43	4.7674
	Age	Below 25	480	4.6583
		26-40	142	4.8803
	Gender	Male	307	4.6743
		Female	315	4.7429
Question 3 "I am sure that my family will allow the medical team to extract my organ for transplantation after I passed away in the event that I	Ethnic	Malay	413	4.0969
		Chinese	166	4.2229
		Indian	43	4.0930
	Age	Below 25	480	4.0833
		26-40	142	4.2887

Statement	Variables		N	Mean
already registered or mentioned my willingness to donate organ	Gender	Male	307	4.1792
		Female	315	4.0825

B. Youth attitudes towards presumed consent of organ donation

In this section, there were three questions measuring youth's attitudes towards informed consent of organ donation. Six levels of Likert Scale were employed namely strongly disagree, disagree, slightly disagree, slightly agree, agree and strongly agree. Mean of each item was utilized as the indicators to examine the attitude of youth under IC. Demographic factors such as ethnic, age and gender acted as independent variables of this study and the attitude towards presumed consent of organ donation represents dependent variable of this study.

Table II depicts youth attitudes towards presumed consent of organ donation based on ethnic, age and gender. The first question asked about youth's opinion whether it is convenient to register as an organ donor. Based on Mean result, in terms of ethnicity, Indian is slightly higher than Malays and Chinese (M=3.9767) perceived ease of registering as a donor organ. Meanwhile, who aged more than 26 and female is more perceived ease of registering as a donor organ.

Second question asked about youth's confidence level on medical team to save their life first before transplantation process begins. In terms of ethnicity, Malays are slightly higher than other races (M=4.4140) and have a confidence on medical team to save their life first before transplantation process begins. Other than that, female youths aged more than 26 years old are more confident towards medical team in saving the life of youth before transplantation process begins.

Third question asked about youths believe that their family will allow the medical team to extract their organ for transplantation after they passed away in the event that they already registered to donate organ. In terms of ethnicity, Indian is higher than other races (M=3.8837) believed that their family will allow the medical team to extract their organ for transplantation. In addition, male youths aged below than 26 years old believed more that their family will allow the medical team to extract their organ for transplantation. Based on the three questions, it can be concluded that youth have less positive attitude towards presumed consent as the average Mean is around 3.

TABLE II. YOUTH ATTITUDES TOWARDS PRESUMED CONSENT OF ORGAN DONATION

Statement	Variables		N	Mean
Question 1 "if the policy of opting out has been implemented, I agree that it will be convenient to sign a form to register my objection from becoming an organ donor in this country"	Ethnic	Malay	413	3.8741
		Chinese	166	3.8373
		Indian	43	3.9767
	Age	Below 25	480	3.8250
		26-40	142	4.0282
	Gender	Male	307	3.8632
		Female	315	3.8794
Statement	Variables		N	Mean

Statement	Variables		N	Mean
Question 2 “if the policy of opting out has been implemented, I am sure the medical team will be trying hard to save my life first before they think of extracting my organ for transplantation”	Ethnic	Malay	413	4.4140
		Chinese	166	4.2892
		Indian	43	4.2791
	Age	Below 25	480	4.2854
		26-40	142	4.6620
	Gender	Male	307	4.3648
Female		315	4.3778	
Statement	Variables		N	Mean
Question 3 “in the event that I did not register or mention my objection to become a donor, I am sure that my family will allow the medical team to extract my organ for transplantation when I had passed away	Ethnic	Malay	413	3.5521
		Chinese	166	3.7349
		Indian	43	3.8837
	Age	Below 25	480	3.6729
		26-40	142	3.4577
	Gender	Male	307	3.6417
Female		315	3.6063	

C. Youths' decision to sign out as non-donors towards ethnic under PC policy

Table III portrays youth's decision to sign out as non-donors in PC policy based on ethnicity and gender. The table shows that Malays (N=262) are higher than other races (Chinese N=92, Indian N=27) that opted to sign out as non-donors under PC system. Meanwhile, in terms of gender, female (N=198) is higher than male (N=183) who opted to sign out as non-donors under PC system.

TABLE III. YOUTHS' DECISION TO SIGN OUT AS NON-DONORS TOWARDS ETHNIC UNDER PC SYSTEM

		Decision		Total
		Would sign out	Would not sign out	
Ethnic	Malay	262	151	413
	Chinese	92	74	166
	Indian	27	16	43
Gender	Male	183	124	307
	Female	198	117	315

VI. DISCUSSION

Youths who are willing to donate their organ agreed that if PC policy is being implemented, the medical team will try their best to save their life first before any transplantation process was carry out. The findings of this study indicate that willing donors of youth have a trust and confidence towards the medical team who carry out the procurement process under the PC system. It can be supported by the study done by [12] stated that it is important to have a public trust and confidence towards the medical team in order to ensure successfully implementation of the PC system in the country. As according to [4] found that one of the reasons of failure of PC system in Brazil was because of the lack of public confidence towards the health professionals.

Besides that, findings of the study found that the youths aged below 25 were more willing to sign out as non-donor if PC system is implemented in Malaysia. In other words, most of them were unwilling to donate their organ if PC is implemented. This is

contradicted with the study done by [2] stated that, the group of people who are favorable towards PC are from the young people aged less than 40 years old, single, with high level of education, have previous experience with organ donation or transplantation, have an information about organ donation and have a knowledge of the brain-death concept

In addition, the findings of this study found that the implementation of PC system did not affect the willingness of youths to donate because the number of non-willing donors is still higher than the willing donors. The findings were contradicted with the study done by [11] where they found that legislative affect individual willingness to donate their own organs and with PC system, the individuals will more likely to donate their organ as compared to the IC system.

VII. CONCLUSION

In order to implement PC system in Malaysia in the future, it is important to improve the infrastructure and public education. Moreover, it is important to have a good relationship between the medical team and family members in order to ensure that the family members have been given sufficient information about the organ transplantation process. The organ donors need to inform and interact with their family members if they want to donate their organ after they passed away so that, it will reduce the burden of the family members to make a decision later.

Even though the findings of this study found that the PC policy will increase the number of non-willing donors, but it is not a barrier for Malaysia to overcome the problem of organ shortage because youths already have a confidence and trust towards the medical team. Thus, it is crucial for Malaysia to take necessary actions towards strengthening the perception of the public about the value of organ donation and positive attitude towards donating their organ may save a thousand lives of people and give them new hope to survive.

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