

Educating Secondary School Students about Organ and Tissue Donation Legislation: A Pilot Study

Truong Thi Thu Ha^{1*}, Voo Ke Rui² and Tan Chee Kiat^{3,4}

¹SingHealth Transplant, Singapore

²Holy Innocents' High School, Ministry of Education, Singapore

³Department of Gastroenterology and Hepatology, Singapore General Hospital, Singapore

⁴Duke-NUS Medical School, Singapore

***Correspondence:** Ha Truong, SingHealth Transplant, Singapore Health Services Pte Ltd, Transplant Administrative and Resource Office, Singapore General Hospital, Block 1, Level 3, 1 Hospital Drive, Singapore 169608. Tel: 6576 2598; Fax: 6220 0730; E-mail: ha.truong@sgh.com.sg

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Abstract

Introduction: This pilot study assessed the effect of structured classroom education on the knowledge of and attitudes toward organ and tissue donation among students in a Singapore secondary school.

Methods: A total of 79 secondary school students were randomly assigned to a control group or an intervention group. The intervention group was given a 30-minute lesson with an accompanying brochure about the benefits of organ and tissue donation and the governing legislations. Baseline and post-intervention survey were administered to both groups of participants to evaluate the effectiveness of the intervention. McNemar's test and Pearson's chi-square test were used to measure the difference of knowledge and willingness to donate levels before and after intervention.

Results: The education intervention increased the knowledge of the students about both legislation Acts. In the intervention group, more than 50% students answered correctly all criteria of the Human Organ Transplant Act (HOTA) and the Medical (Therapy, Education and Research) Act (MTERA) eligibility after the lesson ($p < 0.001$.) However, it did not lead to a significant increase in the percentage of students who reported to be willing to donate under HOTA or pledge in MTERA.

Conclusions: This pilot study demonstrated that a single classroom exposure had the potential to increase knowledge levels of organ and tissue donation among secondary school students. However, increase in knowledge was not accompanied by a change in willingness to donate among study participants.

Keywords: Organ donation; Secondary school education; Donation legislation

Introduction

The availability of donated organs to save lives in Singapore has been insufficient to meet demand. From 2011 to 2014, the number of patients on the heart waiting list quadrupled from 5 to 23 and liver waiting list swelled from 24 to 60. Overall, the organ waiting list continued to number at about 500 patients annually [1]. This number is projected to increase significantly in the next few decades as the population ages. Furthermore, this figure excludes the number of people who died while on the waiting list, thus underestimating the true extent of organ need in Singapore [2]. While the shortage of deceased donor organs is a worldwide phenomenon, it has been reported to be more severe in Singapore [3], where the donation rate is as low as 5 per million population (pmp) per year compared to that of 21 pmp in the UK in 2013 [4,5]. The disproportionately low donation rate may be the result of common known barriers to donation. These are cultural reasons [3,6-10], the lack of knowledge and awareness [10,11], religious beliefs [11-13], and negative interaction with health system [6,9,10,14,15]. In Singapore, one incident that could have worsened the situation was a public outcry following media reports of "forced donation" which happened at a restructured hospital in 2007 [16,17]. The articles portrayed the donation process and involved staffs as being insensitive to the grieving family of the donor. Since then, much effort has been made to ameliorate the unfavorable situation, mostly through public awareness campaigns. Examples of past campaigns are mailing of donation pledge cards to households, Live On movement on traditional media, and Transplant Awareness Week in public places [18-21]. Other strategies to increase the availability of donated organs were also employed: legislation amendment, optimization of donor management workflows, and acceptance of extended criteria donors [22-26].

Organ and tissue donation is governed by two main legislation Acts: the Human Organ Transplant Act (HOTA) and the Medical (Therapy, Education and Research) Act (MTERA). HOTA was first introduced in 1987 and amended in 2004 and 2008. The Act permits the retrieval of the kidneys, liver, heart and corneas of all Singapore citizens and Permanent Residents (PR) for the purpose of transplantation in the event of death. This is only applicable to individuals who are above 21 years

old, not mentally disabled and have not opted out [27]. MTERA allows a person of any nationality who is 18 years old and older to pledge his/her all or selected organ and tissue or whole body for the purpose of transplantation, education or research after he/she passes away [28]. The various amendments to the two Acts were done over the years to enable opt-in scheme and encourage more altruistic donation. With the establishment of National Panel of Transplant Ethics committee and legalizing living donor transplant in section IV A of HOTA, there was some promising effect with a gradual increase in the number of living donor kidney transplants in the past five years [29]. However, despite the inclusion of Muslims in HOTA in 2008 and various public awareness campaigns, the number of actualized deceased donors has yet to increase [1]. This issue remains a challenge that needs to be tackled at different levels by multiple stakeholders [30].

Various studies have shown that educational intervention was one method with higher level of success in creating awareness about organ and tissue donation, especially among youths [31-34]. Youths with accurate knowledge about organ donation were found to be likely to report their willingness to donate organ and tissue too [35,36]. A study by Siebelink et al in 2011 showed that children as young as 12 years demonstrated their willingness to think and make a decision about organ donation [37]. Thus, this study aimed to examine the impact of a single classroom exposure on knowledge and attitude toward organ donation among secondary school students. Specifically, we evaluated the efficacy of classroom student-led educational activity and compare against a self-study activity conducted by the students.

Materials and Methods

Study design

This study was carried out with the permission of the Principal and Head of the Department of Science at a local secondary school. The survey instrument was designed by a team of four students with inputs from a teacher over-seeing the project and a researcher representing a transplant organization with a background in public health services. The questionnaire was validated with a group of five students, who had no prior knowledge about the topic and of the equivalent of academic level with the targeted participants. Based on the validation exercise, improvement for clarity and readability was made. The same finalized questionnaire was used for pre- and post- intervention.

The baseline survey was administered online to all the students in two classes in the secondary school. All the students in the two selected class were included in the study. Prior to that, the students had been informed about the project and assented verbally to take part in the activities required by the study. The intervention was conducted only after the online baseline test had been completed by all the students. On the day of the intervention, a coin was flipped to decide which class will receive intervention. Both classes were asked to complete online questionnaire again one week after

the intervention. The online tests allowed the students to maintain their anonymity.

Participants

A total of 79 students in a single secondary school participated in the study. They were all of Secondary 2 level and on equitable level of academic performance and interest in science. Thirty-eight percent of the study participants were female (n=31). Their ages ranged from 13 to 14 years (mean 13.7 years; standard deviation 0.4). High proportion of the students reported to be Buddhist (39.2%), followed by Christian or Roman Catholic (36.7%), free thinker (18.9%) and other religion (5.2%).

Survey instrument

The final questionnaire comprised of five sections. The first section pertained to participants' demographic factors such as gender, age and religion.

The next four sections consisted of questions about HOTA and MTERA. Sections 2 and 4 elicited personal exposure to the two Acts and intention to opt-out of HOTA or pledge into MTERA. Sections 3 and 5 examined the students' knowledge of the two legislation acts in detail.

The questions in the survey were of different formats, which included dichotomous, multiple-choice and open-ended questions. Most of the answer choices given were Yes and No. Some questions allowed the students to choose Unsure.

Educational intervention

The intervention was in the form of education activities led by four trained students. We intended the intervention to be peer-led and school-based as this had been previously reported to have positive effect in health education among youth [38-41]. Under the guidance of two authors these four students designed a presentation and a brochure about the Acts, and the need and benefits of organ and tissue donation. In a single 30-minute classroom lesson, the trained students gave the presentation to the intervention class; the brochure for every participant was given at the end of the presentation. The students in the intervention class were encouraged to ask questions which were answered at the end of the session by the trained students. The trained students were given instruction to provide facts about the legislation in neutral tone, without appearing to convince the participating students to be supportive of organ and tissue donation or to solicit the students to pledge in MTERA when they reach 18 years old. Information on how to opt out of HOTA and opt in MTERA was shown to the students in the intervention group and they were encouraged to make their own decision about organ and tissue donation and inform their family members about their intention.

After the baseline survey, the students in the control class were not given any lesson or brochure. They were told to conduct self-study about the Acts and the benefits of organ and tissue donation. No opportunity was given for this group

to ask questions about the topics either. They made their decisions about organ and tissue donation without the exposure and the influence of the intervention of this study.

Statistical analyses

Data was analysed using IBM SPSS statistics (version 21) for Windows. Descriptive tests were employed for the number of correct answers given by the participants. The effect of intervention measured by differences in knowledge and attitude toward organ donation post intervention were determined by McNemar’s test for before-after effect and Pearson’s chi-square test or Fisher’s exact test for inter-group comparison with a p value of $p < 0.05$ deemed significant. Pearson’s chi-square test and Fisher’s exact test were also employed to explore potential association between willingness to donate and demographic factors.

Results

Efficacy in changing of knowledge and awareness

Tables 1 and 2 compared the net changes in the knowledge and awareness of the two legislation acts of the study participants. Prior to intervention, the control group did better than the intervention group in five out of six multiple-choice questions about HOTA and three out of four questions about MTERA. On the overall, both groups showed better knowledge in the legislations, one week after intervention. Additionally, it was worth noting that both groups reported more sources of information about the Acts after the intervention.

Table 1 Knowledge and awareness about the Human Organ Transplant Act (HOTA).

Question	Answer options	Control Group (n=40)			Intervention Group (n=39)			p value [‡]
		Baseline	Post-intervention	p value*	Baseline	Post-intervention	p value*	
Are you aware of HOTA?	Yes	45.0%	65.0%	0.008	30.7%	93.7%	0.001	0.004
	No	55.0%	35.0%		69.3%	6.3%		
How did you come across the Act? (multiple choices allowed)	Friends & Family	9	11		4	14		-
	Television	13	9		10	11		
	Newspaper	2	5		5	11		
	Internet	8	22		4	6		
	Other (school)	2	3		1	32		
What are the organs included in HOTA?	Liver, kidney, heart and cornea (correct answer)	50.0%	55.0%	Not Significant	30.7%	81.4%	<0.001	
	Liver, kidney and cornea	10.0%	15.0%		5.1%	6.2%		
	Liver, kidney, heart and stomach	10.0%	30.0%		15.4%	12.4%		0.024
	Not sure	30.0%	0%		48.8%	0%		
Who is included in HOTA?	All Singapore Citizens and Permanent Residents aged 21 years old and above	20.0%	55.0%	<0.001	10.2%	78.1%	<0.001	
	All Singapore Citizens and Permanent Resident aged 18 years old and above	2.5%	27.5%		15.4%	18.7%		0.042

	All Singapore Citizens aged 21 years old and above	15.0%	17.5%		15.4%	3.2%		
	Not sure	62.5%	0%		59.0%	0%		
What is the purpose of HOTA?	Transplantation only (correct answer)	17.5%	25.0%	N.S	15.4%	59.4%	<0.001	
	Support research and advancement of medical science only	5.0%	23.1%		23.1%	15.6%		0.042
	Transplantation and research only	47.5%	50.0%		25.5%	25.0%		
	Not sure	30.0%	1.9%		36.0%	0%		
Can one decide to whom his/her organ get donated?	Yes	37.5%	67.5%		35.9%	25.0%		
	No (correct answer)	20.0%	32.5%	N.S	17.9%	75.0%	<0.001	<0.001
	Not sure	42.5%	0%		46.2%	0%		
Would relatives of donors be made to pay for the cost of organ recovery?	Yes	15.0%	35.0%		20.5%	6.3%		
	No (correct answer)	20.0%	65.0%	<0.001	30.7%	93.7%	<0.001	0.004
	Not sure	65.0%	0%		48.8%	0%		
*: intra-group before and after p value								
‡: inter-group after intervention p value								

Table 2 Knowledge and awareness about the Medical (Therapy, Education and Research) Act (MTERA).

Question	Answer options	Control Group (n=40)			Intervention Group (n=39)			p-value
		Base line	Post-intervention	p-value	Base line	Post-intervention	p-value	
Are you aware of MTERA?	Yes	7.5%	32.5%	0.002	5.1%	87.5%	<0.001	<0.001
	No	92.5%	67.5%		94.9%	12.5%		
How did you come across the Act? (multiple choices allowed)	Friends& Family	1	1		1	12		-
	Television	1	1		3	10		
	Newspaper	1	1		3	10		
	Internet	3	10		1	8		
	Other (school)	0	1		1	32		
What is the minimum age to opt MTERA?	16	15.0%	2.5%		23.0%	3.1%		
	17	0%	5.0%		0%	0%		
	18 (correct answer)	22.5%	35.0%	N.S	30.7%	84.4%	<0.001	<0.001
	19	5.0%	2.5%		5.1%	0%		
	20	7.5%	0%		5.10%	0%		

	21	50.0%	55.0%		36.1%	12.5%		
Could foreigner opt in this Act?	Yes (correct answer)	22.5%	60.0%	<0.001	17.9%	78.2%	<0.001	
	No	15.0%	40.0%		23.0%	21.8%		<0.001
	Not sure	62.5%	0%		59.1%	0%		
What is the purpose of this Act?	Medical studies	2.5%	2.5%		10.4%	6.2%		
	Transplantation	12.5%	17.5%		15.3%	22.0%		0.532
	Advancement of medical science	12.5%	7.5%		5.1%	6.2%		
	All of the above (correct answer)	52.5%	72.5%	0.008	28.2%	65.6%	0.002	
	Not sure	20.0%	0%		41.0%	0%		
Other than the other 4 organs mentioned in HOTA, what are other organs can be transplanted? (multiple answers allowed)	Heart valves	17	13		14	23		-
	Vascular tissues	16	16		18	15		
	Trachea	8	16		17	16		
	Skin	8	10		9	23		
	Lungs	18	21		16	24		
	Bone	12	16		15	23		

Within-group knowledge changes were observed in both groups post intervention. The changes in the control group were only statistically significant in questions about awareness of HOTA, eligibility, and cost bearer of organ recovery, but not in the organs included in the Act, choice of recipient and the purpose of the Act. Participants from the intervention group showed greater improvement in their knowledge in HOTA. McNemar’s test showed that this improvement was significant in all six questions (all $p \leq 0.001$).

Between-group tests showed that the improvement in the net knowledge of the intervention class was significant higher than that of the control class. This was applicable to all questions asking about HOTA knowledge with p value ranged from <0.001 to 0.04.

When asked about MTERA, within-group change in knowledge was statistically significant in both groups in a positive direction except for the control group’s results on eligible age to opt in MTERA. More students reported correctly eligibility of MTERA pledger and purposes of the Act one week after the intervention. Similarly to knowledge in HOTA, participants in the intervention group did significantly better in their post-test compared to their counterparts in the control group with an exception of the question about the purposes of MTERA.

Efficacy in changing of attitudes toward organ donation

Table 3 Awareness of benefits of HOTA and Intention to opt out of HOTA.

Question	Answer	Control group (n=40)			Intervention group (n=39)			p value
		Baseline	Post-intervention	p value	Baseline	Post-intervention	p value	
Do you know of anybody who has benefited from HOTA?	Yes	0%	0%		0%	7.6%		-
	No	100%	100%		100%	92.4%		
If you have answered “Yes” to Q3, how did that person benefit from HOTA?		-	-		-	His/her life was saved		-
Would you opt out of HOTA after knowing that you would receive a lower priority should you require organ transplantation in the future?	Yes	30.0%	40.0%	N.S	41.0%	21.8%	0.04	
	No	70.0%	60.0%		59.0%	78.2%		N.S

Table 3 showed the changes in attitude toward organ donation of the two groups of two opposite directions. The percentage of survey participants from the control group reported their intention to opt out of HOTA after the

intervention increased from 30% to 40% but this was not statistically significant with $p=0.125$. In contrast to that, at baseline 41.0% of the participants in the intervention group chose the option of opting out of HOTA when they were told about receiving the lower priority in the waitlist. After knowing more about the legislation, only 21.8% of these same participants remained consistent about their intention to opt out of HOTA. The within-group change was statistically significant with $p=0.04$. There was no statistical significance in terms of between-group attitude after the intervention, measured by the number of the Yes answers in both groups ($p=0.10$).

When asked about intention to pledge organs under MTERA, after the intervention, both groups showed increment in the number of students willing to pledge in (Table 4). However, the net change in willingness was not statistically significant after the intervention. The participants' main reason for doing so was altruism – by choosing: 'I want to help others'. Among those who did not indicate their willingness to donate, the major concern was upsetting family members.

Table 4 Attitude toward MTERA and intention to donate under MTERA.

Question	Answer	Control group (n=40)			Intervention group (n=39)			p value
		Baseline	Post-intervention	p value	Baseline	Post-intervention	p value	
Would you be willing to donate your organs under MTERA?	Yes	67.5%	70.0%	N.S	56.4%	71.8%		
	No	32.5%	30.0%		43.6%	28.2%		
If you have selected "Yes", why? (multiple choices allowed)	I want to help others	18	21		18	23		
	It may benefit my family members	13	16		4	11		
	I would like to contribute to education and research purposes	5	6		6	11		
	Others	0	0		0	0		
If you have selected "No", why?	My family members may be upset	9	5		4	6		
	It challenges my religious beliefs	1	1		3	2		
	I am worried about how my body will be treated after my death	6	6		2	1		
	I want to be able to specify who receives my tissue	3	0		6	2		
	I think my medical history may affect my eligibility	3	3		3	0		
	Others	1 (Fear)	1 (Do not want to help others)	1 (Fear)	0			

Since there was no statistically significant change in willingness to donate before and after intervention, willingness to donate at baseline of all study participants was studied in relation to their demographic factors and sources of information that the students reported (Table 5). There was no

statistically significant association between the students' willingness and their religion, gender and source of information. No further modelling analysis was conducted to identify predictors of willingness as all. p -value of univariate tests were greater than 0.1.

Table 5 Association between all participant's willingness to donate organs prior to intervention and other demographic information and source of information.

Factor (number of willing participants/total participants, percentage)	Odds ratios (95% CI)	p-value
Gender		
Male (28/48, 58.3%)	1	
Female (21/31, 67.7%)	1.16 (0.83 – 1.63)	N.S
Religion		
Buddhism (19/31, 61.3%)	0.42 (0.11 – 1.58)	
Christianity/Catholicism (15/29, 51.7%)	0.29 (0.09 – 1.07)	
Other religions/No religion¥ (15/19, 78.9%)	1	N.S
Source of information*		
Friends/Family (11/15, 73.3%)	1	
Other sources (television, newspaper, the internet, school)/Not applicable (38/64, 59.4%)	0.81 (0.56 – 1.17)	N.S
Television (14/23, 60.9%)	1	
Other sources (friend& family, newspaper, the internet, school)/Not applicable (35/56, 62.5%)	1.03 (0.69 – 1.51)	N.S
Newspaper (5/7, 71.4%)	1	
Other sources/Not applicable (43/70, 61.4%)	0.86 (0.52 – 1.42)	N.S
The internet (9/12, 75.0%)	1	
Other sources/Not applicable (40/67, 59.7%)	0.79 (0.54 – 1.17)	N.S
School/Other sources (2/3, 66.7%)	1	
Other sources/Not applicable (47/76, 61.8%)	0.93 (0.41 – 2.10)	N.S
¥: Other religions were Taoism, Islam, Hinduism		
*: Choice of source included friend& family, newspaper, the internet, television, school, other. Multiple selections of source were allowed.		

Discussions

One important finding of this study was the participants' poor knowledge of HOTA and MTERA prior to the intervention. This could be due to several reasons: (1) youth's priorities at their current stage of life, (2) the lack of coverage of organ and tissue legislation and/or donation in the lower secondary school syllabus and (3) possibly the inadequacy of awareness campaign outreach. Firstly, youth at this stage of life have common concerns such as acquiring the right set of life skills, academic progression, discovering of their passion and calling [42]. They probably do not proactively seek for information

about nor advocate for this topic. Secondly, organ transplantation is only mentioned briefly in their secondary curriculum. The context of organ transplantation in this instance is restricted to the use and limitation of technology aspect and the moral ethical aspect of transplantation [43,44]. It is neither a compulsory topic in the curriculum nor a tested content for the lower secondary school students. Therefore, it was possible that students had very limited exposure to such topic during school lesson. Finally, the inconsistent and scattered public outreach campaigns might have caused low awareness at baseline study. The most common source of information reported by survey participants was television. We did not go further to ask if the programmes recalled were awareness media campaigns by the relevant government agency or content from documentary or drama. These campaigns might have left minimal impact on this survey's participants or did not reach the study participants at all, hence the low reported awareness.

Another finding that concerned us was that the internet was reported as the most common source of information. This came with two consequences: (1) our inability to verify the accuracy of online source of information and (2) the confirmation that online media could be a useful tool in capturing youth's attention. In the survey, we did not ask the students in detail which source of internet i.e. website, forum, etc. they used to obtain information about organ and tissue donation. Inaccurate reporting information from unverified source could hamper efforts of the past and current awareness campaigns. This is due to biasing hazard of information, i.e. readers form a biased view of certain matter after acquiring erroneous or misleading information [45]. Exposure to inaccurate or falsely reported articles could lead the students away from the truth. We did not assess the students' ability to read critically of information provided to them online neither. Thus, the impact on knowledge about organ and tissue donation could be hard to predict when there was no trained speaker present to explain and verify. On the other hand, the fact that the students turned to the internet as a frequent source to find out more information presented an opportunity for educators and campaigners to better design their awareness initiatives. In fact, this strategy has been employed by overseas organization to engage the online community about the topic via social media and viral online effect with success to a certain extent [46,47]. Perhaps, this strategy should be considered in Singapore too, especially when 87% of households in Singapore have access to the internet [48].

Most importantly, findings of this study showed that structured classroom exposure was effective in increasing (1) knowledge about legislation compared to self-study method and (2) communication frequency. Firstly, this result is in concordance to previous study done by other research groups in the Netherlands, Germany and the United States [33,49,50]. With guidance from trained speakers with knowledge in the topic, the students would not only gain better understanding of the current situation and their rights in the matter, they could also actively participate in making decision. Secondly, there were 12 students reported discussing the topic with their friends and family post intervention versus only one

student did so before the intervention. If their loved ones continued to learn more about organ and tissue donation, the awareness among the public could have been raised indirectly. Other indirect effect due to this communication was the potential increase in willingness to donate. Previous studies showed participants who communicated their wishes to donate organ were also willingness to consent to their next-of-kin's donation [51-54]. Under MTERA, consent from a next-of-kin is needed for donation of organs and tissues other than the kidneys, the liver, the heart and the corneas. Knowing the potential donor's wish would help the next-of-kin in the consenting process. Thus, the structured classroom lesson served not only to equip the students with the right knowledge but also to encourage the students to speak to their family about the topic.

This is a pilot study with small sample size, yet the results showed promising efficacy of the education intervention. In future, we would like to explore if there is sufficient support from teachers of secondary schools in Singapore to discuss this subject in their classrooms. This will have to be carefully thought and planned with proper development of lesson on such a sensitive topic. Besides the small sample size, other shortcomings of the study were the lack of information on the students' and the overseeing teacher's organ pledger statuses, their knowledge about the topic prior to the study, and any potential association between the school's religious affiliation (Catholicism) to the topic. This is because the teachers' and the school's engagement in public health issue as well the school's religion have been found to be a factor influencing attitudes toward organ/tissue donation [55]. Furthermore, we did not probe the control group about the source of information they gathered on the topic of organ and tissue donation and transplantation. As mentioned earlier, inaccurate online reports potentially created a negative impression and led to biased ideology about the topic among the students without proper guidance from a trained teacher. Perhaps future study should consider this prospect and provide the students with an online link to an official platform with an accurate source of information.

Conclusion

In summary, this study demonstrated that a single exposure to structured educational activities was effective in educating lower secondary school students about the benefits of organ and tissue donation and the governing legislation. Both groups of the students in the study reported to be more willing to donate organs under MTERA. We would like to recommend more in-depth study with larger sample size to explore the potential of such educational activities. In the far future, if the results of a larger study confirm our findings, we hope there will be partnering of national healthcare agencies and education institutions to consider providing classroom lesson about organ and tissue donation and transplantation to students so that they can make an informed decision about this topic.

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Conflict of interest statement

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