

A web-based educational intervention module to improve knowledge and attitudes towards thalassaemia prevention in Malaysian young adults

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ABSTRACT

Background: Thalassaemia is a public health burden in Malaysia and its prevention faces many challenges. In this study, we aimed to assess the effectiveness of a web-based educational module in improving knowledge and attitudes about thalassaemia prevention amongst Malaysian young adults.

Methods: We designed an interactive web-based educational module in the Malay language wherein videos were combined with text and pictorial visual cues. Malaysians aged 18-40 years old who underwent the module had their knowledge and attitudes assessed at baseline, post-intervention and at 6-month follow-up using a self-administered validated questionnaire.

Results: Sixty-five participants: 47 Malays (72.3%), 15 Chinese (23.1%), three Indians (4.6%) underwent the module. Questionnaires were completed at baseline (n=65), post-intervention (n=65) and at 6-month follow-up (n=60). Out of a total knowledge score of 21, significant changes were recorded across three time-points- median scores were 12 at pre-intervention, 19 at post-intervention and 16 at 6-month follow-up (p<0.001). Post-hoc testing comparing pre-intervention and 6-month follow-up scores showed significant retention of knowledge (p<0.001). Compared to baseline, attitudes at 6-month follow-up showed an increased acceptance for "marriage avoidance between carriers" (pre-intervention 20%, 6-month follow-up 48.3%, p<0.001) and "prenatal diagnosis" (pre-intervention 73.8%, 6-month follow-up 86.2%, p=0.008). Acceptance for selective termination however, remained low without significant change (pre-intervention 6.2%, 6-month follow-up 16.7%, p=0.109).

Conclusion: A web-based educational module appears effective in improving knowledge and attitudes towards thalassaemia prevention and its incorporation in thalassaemia prevention programs is potentially useful in Malaysia and countries with a high internet penetration rate.

KEY WORDS:

Attitudes, knowledge, thalassaemia, health education, web-based

INTRODUCTION

Thalassaemia is a recessively inherited disorder of haemoglobin synthesis characterised by reduced or abnormal synthesis of the alpha or beta globin chains that form the adult haemoglobin. Patients affected by the severe forms of this condition suffer from severe anaemia from an early age and require lifelong regular red blood cell transfusions for survival and to maintain a reasonable quality of life. The blood transfusions however, lead to an iron overload in the heart, liver and endocrine organs, where chelation therapies which are burdensome and expensive have to be instituted to prevent damage to these organs.¹

An estimated 1.5% of the global population are carriers of beta thalassaemia, with about 60,000 symptomatic individuals born annually, the great majority of whom are in the developing world.² In South-east Asia, the prevalence of *alpha*-thal-1, beta-thalassaemia and HbE gene is estimated to be 3-30%, 2-9%, and 10-50%, respectively.³ In Malaysia, the carrier rate was estimated to be 4.5% for the beta-thalassaemia gene⁴ and 3%-40% for HbE trait.⁵ An estimated direct cost for the management of one thalassaemia major patient who survives to the age of 10 to 30 years old in neighbouring Thailand is between 1.3 to 6.6 million Baht (USD32,500-185,166)³ and in Malaysia, the cost is about RM3million (USD720,000) for the first 30 years of their lives.⁶

Due to the high burden of the disease and limited resources especially in developing countries, it is essential to have strategies in place to prevent the birth of children with thalassaemia major.³ Many countries with a high carrier rate employ preventive strategies which involved increasing awareness in their population and screening so as to identify carriers. Consequently, reproductive options can be offered to those found to be thalassaemia carriers to avoid giving birth to an offspring with thalassaemia major. These options may vary from avoidance of marriage between carriers, avoidance of pregnancy, adoption, selective termination of affected pregnancies to pre-implantation genetic diagnosis.

In Malaysia, as part of the National Thalassaemia Prevention and Control program launched by the Ministry of Health in year 2004, mass public education campaigns were

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carried out especially in the print and electronic mass media. Consequently, public awareness about thalassaemia has increased over the years but knowledge gaps and inadequate screening uptake were still noted.⁷⁻¹⁰

Mass communication media including print and broadcast media, as well as nationwide health campaigns have traditionally been effective for raising public awareness about thalassaemia.¹¹ However, due to the unprecedented spread of the internet, it is now considered the most rapidly growing source of health information.¹² Web-based resources have been developed across a broad range of health areas and act as important tools to educate the public, patients and health care professionals.^{13,14} To the best of our knowledge so far, there is no published study on the impact of web-based education on thalassaemia prevention.

In this study, we designed a brief web-based educational module and we aimed to determine its effectiveness in improving knowledge and attitudes about thalassaemia prevention amongst young Malaysian adults in the immediate post-intervention period and six months after the intervention

MATERIALS AND METHODS

Design of the web-based educational intervention

The development of the educational module and its content was in the Malay language (the national language of Malaysia) and our team consisted of three clinicians experienced in thalassaemia. The content included an explanation about thalassaemia and its complications, treatment with blood transfusion and chelation agents and the challenges of achieving cure by transplant. We included information about its mode of inheritance and prevention methods, such as avoidance of marriage between carriers and if married couples are both carriers, options such as family planning, limiting the number of children and prenatal diagnosis. These were discussed with a final message that urged the viewers to screen at the various health facilities in the countries. Videos of the clinicians explaining the agreed content were then recorded. Both text and pictorial visual cues were embedded in the videos to improve comprehension.

The edited footage was then embedded into an interface that was developed using cloud technology. Its webpage used tools from Weebly for designing the layout with the videos hosted on YouTube which was then converted into a Chrome application as a method of delivery. The module allowed viewers to choose their topics of interest by using a navigation menu located on the left side of the screen. Figure 1 shows a screenshot of the module. The videos for each topic ran from one to three minutes and the total duration to view all the videos consecutively was 19 minutes and 24 seconds. The cost of creating this module was RM4,900 (about USD1101) in which the amount was paid to a private company for professional videography in two locations (Kuala Lumpur and Johor Bahru) and video editing services. The remainder of the work to create the educational module which included incorporation of text and pictorial visual cues, development of the interface and hosting on a free

webpage were mainly undertaken by a skilled team member. The experts featured in the video were members of the research team.

Questionnaire Design

A structured questionnaire assessing the participants' knowledge, attitudes and practice about thalassaemia was designed to be administered pre-intervention, post-intervention and during follow up six months post-intervention. Knowledge about thalassaemia was assessed using 21 true-false questions across four domains: (1) general aspects of thalassaemia (7 items); (2) thalassaemia major (5 items); (3) thalassaemia minor (5 items) and (4) thalassaemia prevention (4 items). Participants were given three options of either "true", "false" or "don't know" where a correct response was given a score of one whereas a wrong response or "don't know" response scored as zero. A score of 16 or above in the 21-item knowledge survey was considered satisfactory and this benchmark was decided by our team members who had clinical expertise in the field of thalassaemia.

The 21-item close-ended knowledge questionnaire had good internal consistency with a Cronbach alpha coefficient of 0.89 in our study. Participants' attitudes towards preventive measure were assessed with four questions which utilised a 5-point Likert scale ranging from "strongly agree" to "strongly disagree". Their practice in terms of uptake of preventive measures such as screening was also evaluated. The questionnaire was modified from previous publications^{9,15} and underwent content validation by our panel of clinicians with expertise in thalassaemia.

The questionnaire was initially developed in English and then translated into the Malay. Back translation was conducted by a different translator and these versions were reviewed and edited by the principal investigator. The Malay questionnaire then underwent rigorous pilot testing within a focus group before it was finalised and modified into an electronic version. We also included questions to capture the participants' characteristics in the pre-intervention version whereas the post-intervention questionnaire has additional questions to obtain feedback with regards to the module.

Sample size

As there were no published reports about web-based education in thalassaemia, we used findings from a study which investigated the effectiveness of education workshops on thalassaemia¹⁶ for sample size determination using GPower software.¹⁷ Based on a 20% attrition rate and a power of 80% with a two-sided alpha of 0.05%, a minimum sample of 48 participants were needed for our study.

Setting and conduct of study

The study was conducted in year 2015 at the Monash University Malaysia's Clinical School located in Johor Bahru, Johor. Flyers were distributed in a community clinic and a shopping mall within five kilometres from the study site inviting members of the public who were Malaysians aged 18 to 40 years old to participate. Those who volunteered were enrolled if they fulfilled our inclusion criteria which were: Malaysians aged 18 to 40 years old with basic literacy in

Malay. We excluded those with thalassaemia disease such as thalassaemia major or thalassaemia intermedia. A sum of RM50 (USD12) was given to each participant to cover for travelling expenses.

Written informed consent was obtained from each participant. After completing a self-administered pre-intervention questionnaire, participants underwent the educational module delivered via a web-based interface where they were free to navigate through the topics without any restriction or compulsion. Their online viewing of each topic was tracked electronically. Immediately after the participants have completed the module, they underwent a post-intervention questionnaire. They were not provided further access on the educational module. Six months later, they were requested to fill up an on-line version of the same questionnaire sent via a link to their email or requested to return to the research site to complete the survey. All data was anonymised, and participants were requested to enter a four-digit identification code of their choice in all their questionnaires to enable us to link the three versions for analysis. This interventional study used a single group pre-post study design and there was no control group involved in this study.

Statistical Analysis

The distribution of knowledge score was skewed hence non-parametric tests were used when analysing the scores as a continuous variable. We compared the total knowledge scores across the three time periods using Friedman test followed by post-hoc pairwise comparison using Wilcoxon Signed-Rank test with a Bonferroni adjusted alpha value. We used Mann-Whitney-U tests to compare knowledge scores between different groups at a single test period. We used McNemar test to compare the proportion accepting the preventive measures across two time points. Data analysis was conducted using IBM® SPSS® Statistics 22 and statistical significance was set at $p < 0.05$.

APPROVAL

This study was approved by the Malaysian Ministry of Health Research and Ethics Committee (NMRR -14-735-21495).

RESULTS

Participants' characteristics

Sixty-five participants underwent the educational module and completed both the pre-intervention and post-intervention questionnaires. Their characteristics are presented in Table I. They were from different ethnicities with Malays (72.3%) followed by Chinese (23.1%) and Indians (4.6%). In addition, 73.9% had post-secondary education and 95.4% had internet access spending an average of 5.5 hours daily on the internet. Thirteen participants (20%) had never heard of thalassaemia and 53 (81.5%) were never screened for this condition. The reasons most commonly cited for not being screened were "uncertainty on where to get tested" (54.7%), "unsure of reasons for testing" (45.3%) and "beliefs that the individual risk was low" (32.1%). Of those who were screened ($n=12$), ten were not carriers whereas the remaining two were unsure of their status.

Sixty participants (91%) completed the six-month follow up questionnaire. The remaining five participants who failed to respond to our request to complete the follow-up survey were compared to the sixty participants in terms of their demographic characteristics and their pre and post-intervention knowledge scores and attitudes in which we found no significant differences between these two groups.

Knowledge

Scores across the three time points for the 60 participants who completed all three sets of questionnaires were compared. Out of a total score of 21, their median score changed significantly during the three time points – median scores were 12 at pre-intervention and increased to 19 post-intervention and decreased to 16 at 6-month follow-up ($p < 0.001$) (Figure 2). Post-hoc testing comparing pre-intervention and 6-month follow-up scores still showed significant knowledge gain ($p < 0.001$). Converting the 21-point scores into percentages, scores increased by 33.3% on average from pre-intervention to post-intervention ($p < 0.001$) and decrease by 14.3% from post-intervention to 6-month follow-up ($p < 0.001$) with a net gain of 19% from pre-intervention to the 6-month follow up period ($p < 0.001$). Proportion of participants achieving a satisfactory score (16 or above) was 9.2% pre-intervention, 86.2% post-intervention and 56.7% on follow up.

The scores of participants based on their characteristics were compared at each time points as shown in Table II. Baseline knowledge scores was significantly higher amongst participants who were females and younger than 30 years of age, and not surprisingly amongst those who have heard of thalassaemia before. Interestingly, a similar trend was again noted on re-testing 6 months later despite no differences between these groups in the immediate post-intervention period.

Attitudes and Practice

Table III presents the attitudes pre, post and six months post-intervention where we have merged the responses of "1" (strongly agree) and "2" (agree) together as agreement with the respective measures. Most participants agreed for screening throughout the study period. Their acceptance towards avoidance of marriage between carriers and prenatal diagnosis increased significantly post-intervention and this change in attitudes was observed on reassessment six months later. On the other hand, acceptance towards termination of pregnancies was poor in the three time periods assessed with no significance difference ($p=0.109$) despite a slight increase from 6.2% pre-intervention to 16.7% six months later. Acceptance towards selective termination at 6 months follow up was independent of gender ($p=0.725$), ethnicity ($p=0.725$), religious background ($p=0.610$), household income ($p=0.757$) or educational level ($p=0.905$) using Chi-Square test. The proportion of participants who had not been screened for thalassaemia at pre-intervention period (53/65, 81.5%) was not significantly different at six months follow up (48/60, 80%) ($p=1.00$).

Usage and Feedback on computer module

On average, the participants spent 22.8 minutes ($SD=2.9$) to undergo the educational module. The most popular video

Table I: Characteristics of Participants (n=65)

Gender	Male	27 (41.5%)
	Female	38 (58.5%)
Age (years)	Mean (SD)	29.4 (5.7)
	Range	18–39
Age (years)	≤30	37 (56.9%)
	>30	28 (43.1%)
Marital status ^a	Single	23 (35.4%)
	Married	41 (63.1%)
Number of children	Median (IQR)	0 (2)
	Range	0–3
Ethnic background	Malay	47 (72.3%)
	Chinese	15 (23.1%)
	Indian	3 (4.6%)
Religion	Muslim	47 (72.3%)
	Christian	9 (13.8%)
	Buddhist	6 (9.2%)
	Hindu	3 (4.6%)
Highest Educational Levels	Secondary	17 (26.2%)
	Diploma/College	25 (38.5%)
	University	23 (35.4%)
Employment	Housewife	2 (3.1%)
	Student	6 (9.2%)
	Unemployed	2 (3.1%)
	Part time	1 (1.5%)
	Full time	53 (81.5%)
Household income/month (MYR)	<3000	22 (33.8%)
	3000-5000	25 (38.5%)
	>5000	18 (27.7%)
Internet access	Yes	62 (95.4%)
	No	3 (4.6%)
Internet usage/day (hours)	Mean (SD)	5.5 (3.3)
	Range	0–16
Ever Heard of “thalassaemia” ^a	Yes	51 (78.5%)
	No	13 (20%)
Screened for thalassaemia	Yes	12 (18.5%)
	No	53 (81.5%)

^aOne participant did not respond to the stated question

viewed was on the topic “Can thalassaemia be cured?” Feedback on the module using the 5-point Likert scale was extremely positive with 98.5% of the participants in agreement that (1) the information presented was easily understood, (2) improved their knowledge and (3) increased their confidence in deciding about screening and prevention whereas 96.9% found it user-friendly. In addition, 66.2% of participants found the amount of information presented in the module to be satisfactory whereas 29.2% and 4.6% reported too much and too little information respectively.

DISCUSSION

Our small study showed that web-based education has the potential to improve knowledge and attitudes even after a period of time. In fact, various health education programmes have successfully utilised computer-aided programmes to disseminate information and change behaviour in a cost-effective manner.¹⁸⁻²⁰ When a module is tailored to be delivered web-based, these educational material can reach out to a huge population, even countries with limited resources have experienced a significant increase in household internet with youths being the relatively most networked group.²¹ Similarly in Malaysia, computer literacy rate for those aged 5-69 years has reached 45% in year 2010

Table II: Socio-demographic differences in knowledge scores pre-intervention, immediate post-intervention and six-month post-intervention

		Knowledge Scores (total =21)					
		Pre-Intervention (n=65)		Post- Intervention (n=65)		Six-month post-intervention (n=60)	
		Scores	P	Scores	P	Scores	P
Total		12 (6)		19 (4)		16 (4)	
Gender	Male	9 (12)	0.016	18 (4)	0.435	14 (3)	<0.001
	Female	12.5 (4)		19 (3)		17 (3)	
Age (years)	≤30	13 (6)	0.011	19 (4)	0.062	17 (4)	0.022
	>30	10 (11)		18 (7)		15 (4)	
Marital Status	Not married	12 (6)	0.938	19 (5)	0.475	16 (4)	0.756
	Married	12 (7)		18 (3)		16.5 (5)	
Ethnic	Malay	12 (6)	0.248	19 (3)	0.459	16 (5)	0.299
	Non-Malay	10 (11)		19 (5)		16 (4)	
Highest Education level	Secondary school	10 (5)	0.227	16 (2)	0.002	16 (4)	0.384
	Diploma/College/ University	12 (7)		19 (3)		17 (5)	
Monthly household income (RM)	<3000	11.5 (6)	0.818	17 (4)	0.218	16 (4)	0.950
	>3000	12 (5)		19 (4)		16.5 (6)	
Heard of thalassaemia before	Yes	13(5)	<0.001	19(3)	0.129	16.5 (4)	0.010
	No	0(4)		18(4)		13 (5)	
Screened for thalassaemia	Yes	14(2)	0.009	19.5 (3)	0.142	17.5 (5)	0.077
	No	10.5(6)		18.5 (4)		16 (5)	

Scores expressed as Median (±IQR)

p values are based on comparisons between two groups at a single time-point (Mann-Whitney test)

Table III: Agreement for preventive measures pre-intervention, immediate post-intervention and six-month post-intervention

	Pre-Intervention (n=65)	Post-Intervention (n=65)		Six-month post-intervention (n=60)	
	n(%)	n(%)	p	n (%)	p
The public should undergo premarital screening for thalassaemia	57 (87.7)	65 (100)	0.008	58 (96.7)	0.180
Couples who are carriers should not marry each other	13 (20.0)	32 (49.2)	<0.001	29 (48.3)	<0.001
Couples at risk of conceiving a child with thalassaemia major should undergo prenatal diagnosis	48 (73.8)	61 (93.8)	0.001	56 (86.2)	0.008
Pregnancy with a foetus affected by thalassaemia major should be terminated.	4 (6.2%)	7 (10.8%)	0.453	10 (16.7)	0.109

p-value obtained were in comparison to the pre-intervention questionnaire (McNemar test)

and is set to increase further.²² Broadband penetration demonstrated a similar trend with youths showing a much higher internet penetration rate at 94.9% compared with the overall population rate at 65.8%.²¹ Therefore, any public health education programmes especially those targeted at the youths such as thalassaemia awareness should consider harnessing the internet as a potentially powerful tool that can allow widespread dissemination of information in a cost-effective manner. In addition, the delivery of web-based education can be tailored to mobile devices such as hand

phones and tablet computers considering the wide usage of these devices. In Malaysia, hand phone penetration rate exceeds 100 subscriptions per 100 inhabitants due to multiple subscriptions²³ with users dominated by young adults and about two-third (63.3%) of users accessed the internet through their hand phones.²⁴

In Malaysia, thalassaemia screening on a voluntary basis has been practised for many years where free testing is available at multiple government health facilities spread

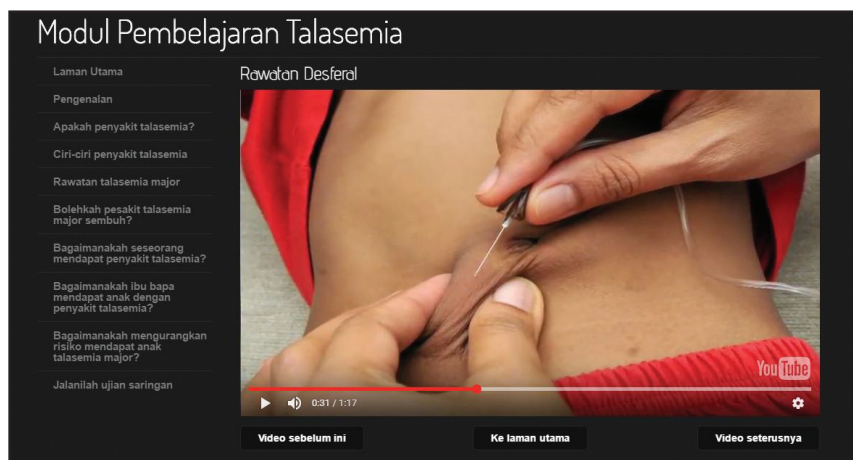


Fig. 1: Screenshot of web-based interactive educational module.

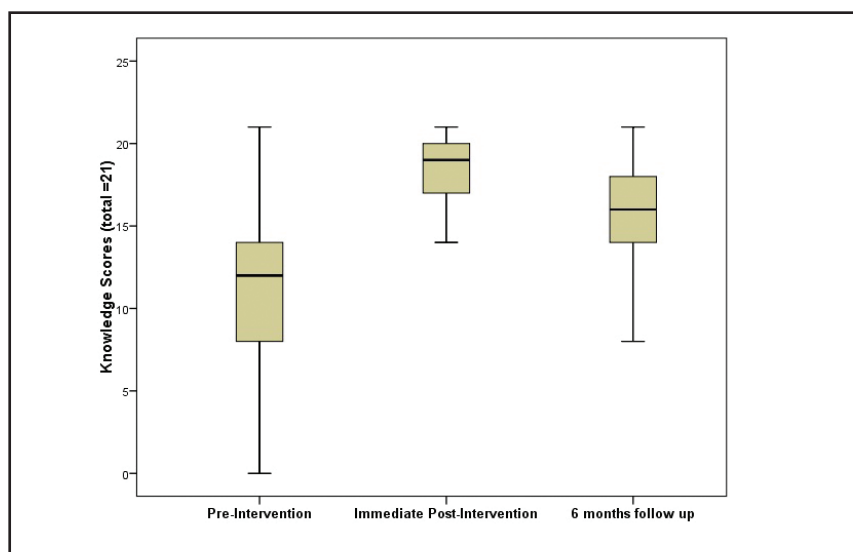


Fig. 2: Knowledge scores across three time points.

throughout the country. In year 2016, Malaysia has embarked on large scale population screening amongst 16-year old secondary school students.²⁵ With the increased identification of carriers, our prevention strategy emphasizes on marriage avoidance between carriers. We note that the acceptance of this measure appears to improve after intervention in our study. Whether known carriers in Malaysia will accept this in actual practice remains unknown.

Marriage rate amongst carriers varies greatly between regions depending on the availability of prenatal diagnosis and multiple socio-cultural and religious aspects.²⁶ Prenatal diagnosis followed by selective termination in some countries have resulted in a remarkable reduction in births of children with thalassaemia.²⁷⁻²⁹ In Malaysia, despite the agreement for prenatal diagnosis, termination of affected foetuses remained generally unacceptable as reflected in the results from our study and larger studies conducted among the Malaysian public^{9,10} and parents of children with thalassaemia.³⁰ Further studies are needed with regards to the multiple factors that influence the attitudes and actual decision-making on

reproductive options among thalassaemia carriers in Malaysia.

Despite the generally positive feedback we received on our educational intervention, we are aware that web-based education has several limitations. Besides needing access to the internet, the use of online educational material requires the ability to read text, use information technology and appraise the content of these tools to make health decisions and thus requires some amount of literacy skills.³¹ It has to continuously evolve to meet the changing needs and preferences of the society such as improving on its attractiveness and interactive features. Web-based education is an efficient way of reaching large numbers of people but tend to attract a select and self-selected population which is disproportionately female, well-educated and health conscious.³² Therefore, it is vital that a comprehensive, multi-faceted health promotion strategy includes other more “traditional” channels such as mass media and face-to-face dissemination of information so that the appropriate information can be delivered effectively to the target population.

Our study has its limitations. Although our participants are from multiple ethnic groups, their educational levels are somewhat higher than the general population. Having volunteered to participate in this study, they were likely to be more motivated to seek and understand the information delivered compared to the general public. Our findings that demographic characteristics such as female gender and younger age group have better knowledge should be validated by larger studies prior to establishing the target population who will benefit most from such intervention. Nevertheless, we have demonstrated the potential of a local contextualised web-based education in improving knowledge and attitudes about thalassaemia. Further studies in this area should cover a larger population and perhaps focus on unmarried young adults. Their knowledge, attitudes and more importantly their practices should be studied so that the multiple factors contributing to birth of children with thalassaemia could be identified and hopefully addressed in future prevention programs.

CONCLUSION

A web-based educational module improves knowledge about thalassaemia and attitudes towards preventive measures in Malaysia. As an increasing number of youths in developing countries are embracing the internet as an important source of information, health education targeted at them should use internet-based technologies as it provides unique possibilities for public health education without the barriers of distance, time and space in a cost-effective manner.

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