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Eduvariome HVP Malaysia: Promoting Knowledge and Awareness on Thalassaemia among Secondary School Students in North-East of Peninsular Malaysia

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Abstract

Background and objective: Thalassaemia prevention which includes public education, screening and pre-marital counselling, forms important components of a prevention programme. The EduVariome programme under MyHVP Malaysia is an educational intervention programme developed to increase awareness on thalassemia and the importance of thalassemia screening. This study aimed to assess the effectiveness of this an educational intervention programme in increasing the awareness of secondary school students regarding thalassaemia. **Method:** This study was conducted among secondary school students aged between 14 to 17 years old. The programme was conducted by giving a lecture in the form of a forum related to thalassaemia. Questionnaires to assess the participants' sunderstanding of the disease were distributed before and after the lecture. The data was analyzed using SPSS Version 22. **Results:** A total of 422 secondary school students in Kelantan state took part in this study. About thirty six percent (36.3%) were male and 63.7% were female. Out of the total respondents, 69.9% had a general knowledge on thalassaemia before the intervention. Knowledge scores were significantly increased after the educational intervention. The total knowledge score, general knowledge on disease and knowledge on the disease prevention were significantly increased after educational intervention from 3.34 (1.95) to 5.15 (1.60), from 2.00 (1.18) to 2.99 (0.96) and from 1.35 (1.08) to 2.17 (0.90), respectively. **Conclusion:** The educational intervention done by MyHVP EduVariome programme proved to increase the knowledge of the participants about thalassaemia. The knowledge should be delivered through interesting approach as it would impart valuable education and enhance the awareness regarding thalassaemia. With this understanding, it can empower people to volunteer, accept and support thalassaemia carrier screening carried out by the government to prevent thalassaemia child birth in the future.

Keywords: MyHVP, EduVariome, Thalassaemia Awareness, Thalassaemia Knowledge

Introduction

Thalassaemia is a type of haemoglobin disorder that causes serious global public health concern due to the alarming number of new cases every year. There are about 400,000 newborn babies with a serious haemoglobin disorder per year (Weatherall, 2010). Thalassaemia is more prevalent in countries located on the tropical and sub-tropical areas where malaria is or was endemic or also known as 'Thalassaemia Belt', extending from the Mediterranean, throughout Middle East, Central Asia, India and Southeast Asia (De sanctis et al., 2017) including Malaysia. It is estimated that about 5% of Malaysians are carriers where the majority having beta thalassaemia or alpha thalassaemia or heterozygosity of other haemoglobinopathies (Malaysia Thalassaemia Registry Report, 2019). Malaysia is a fast developing country with an estimated population of 32.6 million in 2019 and encompasses a majority of Bumiputera; whose includes Malays and Bumiputera Sabah and Sarawak (69.3 %), followed by Chinese (22.8%), Indian (6.9%) and minority groups that constitute the remaining 1% of the population (Department of Statistic Malaysia, 2019).

Thalassaemia is a single-gene disorder that results in the reduction or absence of alpha or beta globin polypeptide chain synthesis. Clinically, they are classified as thalassaemia major, intermedia and minor (Old, 2003). Patients with thalassaemia major presents with haemoglobin level of <7.0 g/dL. The main treatment for thalassaemia major is regular blood transfusion for survival throughout life. However, regular blood transfusions will lead to other complications such as internal organ failure due to iron overload. Thalassaemia major includes homozygous β^0-thalassaemia and homozygous α^0-thalassaemia (Weatherall and Clegg, 2001). The latter being the most severe type of disease where patients die in utero or soon after birth (Jatavan et al., 2018). Whereas, thalassaemia intermedia shows mild to moderate anaemia with haemoglobin level of $\geq$ 7.0 g/dL. These patients are also known as Non-Transfusion Dependent Thalassaemia (NTDT) or some may occasionally need blood transfusions (Musallam et al., 2013).

The lack of knowledge and awareness about the disease and its consequences lead to social stigmatisation towards patients with thalassaemia and their families. Thus, there is no doubt that thalassaemia affects both the physical and mental well-being of the patients and their care-givers. Furthermore, the stigmatisation, psychosocial and cultural issues may serve as barriers to disease disclosure and subsequently affecting the preventive measures that needs to be taken to reduce the incidence of thalassemia in the population. In a study by Ahmed and his co-researchers, they had reported that due to religious grounds, Muslim couples refuse to undergo prenatal diagnosis (Ahmed et al., 2006). However, studies on knowledge, attitude and practices related to thalassaemia are relatively scanty in the Malaysian context.

The difficulties of population screening for the prevention of this inherited disease have been a major discussion in many countries for so many years. However, a promising result was seen by reduction of new thalassaemia birth in a few countries which practice comprehensive national prevention programmes, such as Italy, Greece, Cyprus, the United Kingdom, France, Iran, Thailand, Australia, Singapore, Taiwan, Hong Kong and Cuba with motivation moving towards 'Zero Thalassaemia' in the future (Modell et al., 2007). The prevention programmes include public awareness and health education, carrier screening, genetic counselling, prenatal diagnosis and sometimes therapeutic abortion when dealing with life-threatening form of thalassaemia.

Cyprus for example has succeeded in reducing thalassaemia major birth rate from 1 in 250 births to 1 in 4000 births through its comprehensive thalassaemia programme focusing on a variety of aspects especially increasing the awareness among citizens added with mandatory carriers screening before their marriage. Malaysia's neighbour; Singapore, also showing success in reducing new birth rate to less than 1%. Meanwhile in Malaysia, the continuous effort to reduce thalassaemia birth rate are ongoing in hope to achieve a very low birth rate in 2050 (Buang S.N,2018). The Thalassaemia Prevention and Control Programme was started nationally by the Malaysian Ministry of Health in 2004. The prevention programme is intensified by screening school students nationally since 2014 which aim to

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identify carriers and increase public awareness (Ministry of Health, 2019).

With a similar objective to increase awareness on thalassaemia among Malaysians, a non-government organization (NGO) known as Malaysian Node of Human Variome Project (MyHVP) had introduced EduVariome Programme. MyHVP was launched on 9th October 2010; under the leadership of Universiti Sains Malaysia and is currently formed by 71 individuals from 12 Malaysian academic institutions and universities. The establishment of MyHVP received full support from the Malaysian Ministry of Sciences, Technology and Innovation (MOSTI) and Ministry of Education (MOE), local universities and societies such as Malaysian Society of Human Genetics, Genetics Society of Malaysia, Malaysian Society of Bioinformatics and Computational Biology and Medical Genetics Society of Malaysia. To date, MyHVP has succeeded in developing an online database for genetic mutations directly related to genetic diseases which are prevalent in Malaysia, and the Malay whole genome single nucleotide polymorphisms (SNPs) data (Yusuf et al,. 2017).

EduVariome is a programme to raise awareness on genetic diseases focusing on thalassaemia and the importance of pre-marital genetic screening in schools and higher learning institutions. With its tagline "Educating people towards a healthier nation", this one of its kind community knowledge transfer project in Malaysia, focuses on small scale effort in providing additional information to secondary school students to better understand thalassaemia in hope to aid the National Thalassaemia Form 4 Students Screening Programme agenda.

The objective of this study was to evaluate the effectiveness of health education programme on thalassaemia prevention that was designed by MyHVP EduVariome Programme for secondary school students aged between 14 to 17 years old in Kelantan State, Malaysia. According to the World Health Organization, this is the reproductive age range for women, where a person is allowed to marry and have offspring. It is important to provide knowledge on thalasaemia at this age as they have the potential to get married after completing their education.

We hypothesized that after the implementation of the health education programme, the intervention group would have more knowledge and improved their attitude towards thalassaemia and would have greater participation in screening for thalassaemia carrier.

Samples and Methods

There were 422 secondary school students from 25 selected schools in Kelantan state, Malaysia involved in this study from year 2014 to 2018. These 25 schools were selected by MyHVP EduVariome Programme according to their locations in different districts in Kelantan and according to the easy access of the speakers and the secretariats to organise the programme as the programme is considered as community knowledge transfer project. The ethical approval from USM's Ethics Committee was obtained and approval to conduct the programme and to assess the knowledge of the respondent in schools' facilities were obtained from the schools' representatives prior to the events. The EduVariome Programme was approved to be conducted in each school facility by the Education Board as it is considered as a community work from MyHVP.

The educational intervention programme related to thalassaemia was conducted via lectures in a form of forum where specialist for each area such as clinicians, researchers, care-givers, patients and also experts in religious issues had been invited to enhance the knowledge and increase the awareness of secondary school students on thalassaemia. The preparation of the slides and contents for each lecture and for each speaker were decided on the topics of general knowledge of thalassaemia, the signs and symptoms, the diagnostic process, the treatment, prevention and also thalassaemia screening programme. The school's hall was used as the facility to gather about 50-100 secondary school students for each session. Time frame for each session was 5 hours which started with registration, forum and lecture, exhibition of posters and thalassaemia-related game booths, quizzes sessions and closing ceremony.

The pre-questionnaires were distributed before the forum and post-questionnaires were given afterwards. The rationale of the interval was so that the participants had acquired knowledge on thalassaemia and their responses to the questionnaires were the result of the intervention provided and not due to any other source of information from other means including more time to study.

The questionnaires were adapted and modified from previous published literature (Ahmed et al., 2006) and prepared in 2 versions of language i.e Bahasa Melayu (the national language of Malaysia) and English. Questionnaires were structured into pre-and post- questionnaires consisting of 4 parts (pre-) and 3 parts (post-). The questionnaire components were questions pertaining to demographic data knowledge on thalassaemia and its screening test, the attitude of the respondents towards Thalassaemia Screening Programme and the last component was the question on practice or action of respondents' towards Thalassaemia Screening Programme. However, this article only discusses regarding the respondents' knowledge on thalassaemia and its screening test which consist of 7 questions that covered the topics such as;

- A question on what is thalassaemia?
- A question on the treatments for thalassaemia
- A question on the sign and symptoms of thalassaemia
- A question on the characteristics of the thalassaemia carrier
- A question on the target population for thalassaemia screening and
- Two questions on the prevention of thalassaemia disease

The knowledge questions were then categorized into 2 categories; basic knowledge about the thalassaemia and knowledge about thalassaemia prevention. For each question, a correct response was given a score of one and incorrect or 'don't know' was scored as zero. The total possible score were 0 to 7, higher score indicating better knowledge on thalassaemia.

Data analysis

SPSS version 22 was used for data entry and analysis. The socio-demographic characteristics of the participants were analyzed using descriptive statistics (i.e., frequencies, means, standard deviation, median and range), paired sample t-test was applied to access the knowledge score before and after educational intervention on topics of basic knowledge of thalassaemia and knowledge on thalassaemia prevention. Meanwhile, independent sample t-test was applied to access the knowledge score before and after educational intervention for selected demographic characteristic.

Results

There are 422 school students in Kelantan state agreed to be involved in the study which 36.3% are male and 63.7% are female. Data divided into ethnic groups, majority were Malay (98.6%), Chinese (0.2%) and 1.2% were from other races (Table 1).

Majority of the respondents (88.2%) had basic knowledge on thalassaemia as they have heard about thalassaemia before the forum and 69.9% of the respondents know that thalassaemia is a form of inherited blood disease. They knew about thalassaemia from previous forums related to thalassaemia, friends, school teachers, health practitioners, media platforms and also from own family history.

Knowledge scores were significantly increased after the educational intervention. Based on Table 2, the total knowledge score was significantly increased after EduVariome educational intervention from 3.34 (1.95) to 5.15 (1.60). The knowledge on disease (what is thalassaemia, the signs and symptoms and treatment) score and knowledge on the disease prevention score were both significantly increased from 2.00 (1.18) to 2.99 (0.96) and from 1.35 (1.08) to 2.17 (0.90) after the educational intervention event.

A significant improvement in knowledge score was observed in the before forum and after forum in selected socio-demographic characteristic group (Table 3). The knowledge scores between selected socio-demographic characteristic groups were as follows: male knowledge score was significantly higher after forum compared to before forum (from 2.77 (2.18) to 4.81 (1.92)), female score was significantly higher after attending forum 5.33 (1.35) from a score of 3.67 (1.73) before attending the forum, and both lower and upper age group knowledge scores were significantly higher after forum compared to before forum which was from 0.88 (1.21) to 2.36 (1.75) and from 3.61 (1.83) to 5.45 (1.25) respectively.

Table 1. Socio-demographic characteristic of the participants

		Frequency	Percentage
Age			
	14 years old	43	8.0
	15 years old	96	17.8
	16 years old	296	55.0
	17 years old	103	19.1
Gender			
	Male	195	36.2
	Female	343	63.8
Race			
	Chinese	1	0.2
	Malays	532	98.9
	Others	5	0.9
Type of school			
	Boarding school	20	3.7
	Daily school	518	96.3
Religion			
	Muslim	532	98.9
	Buddhist	6	1.1
Have heard about thalassaemia before forum			
	No	63	11.8
	Yes	471	88.2
Know about thalassaemia			
	No	159	30.1
	Yes	370	69.9

Table 2. Total knowledge score for pre- and post-forum

Knowledge score	Pre-forum mean(SD)	Post-forum mean(SD)	Mean difference (95% CI)	p-value
Total score	3.34 (1.95)	5.15 (1.60)	-1.80 (-1.99, -1.61)	<0.001
Knowledge on disease	2.00 (1.18)	2.99 (0.96)	-0.99 (-1.11, -0.88)	<0.001
Knowledge on prevention	1.35 (1.08)	2.17 (0.90)	-0.82 (-0.93, -0.71)	<0.001

Paired sample t-test was applied
*significant level was set at <0.05

Table 3. Comparison of knowledge score within selected sociodemographic groups before and after forum was conducted

Demographic characteristic		Knowledge score		P-value
		Pre-forum mean (SD)	**Post-forum mean (SD)**	
Gender	Male	2.77 (2.18)	4.81 (1.92)	<0.001
	Female	3.67 (1.73)	5.33 (1.35)	<0.001
Age group	Lower	0.88 (1.21)	2.36 (1.75)	<0.001
	Upper	3.61 (1.83)	5.45 (1.25)	<0.001

Independent sample t-test was applied for each demographic characteristic
*significant level was set at <0.05

Discussion

The management of patients especially those with β-thalasaemia major have a great impact on patient psychosocially. This is caused by their need to be on continuous treatment and monitoring in order to minimise thalassaemia complications and prolong their survival. This comes at a cost to their mental wellbeing. It was reported that the rate of psychiatric disorders such as depression and anxiety in children with thalassaemia is higher than those having other chronic diseases (Harteveld et al., 2003).

Patients and their care-takers need to be well informed regarding the disease such as on how the disease is inherited, early signs and symptoms of the disease and future prevention should be delivered via attractive and acceptable medium. Although majority of participants have heard of thalassaemia (88.2%), a marked percentage still remains unaware. To bridge the awareness gap between different ethnic groups, educational efforts are needed. Armeli and team had suggested that community-based education programme works best to address the knowledge disparities in multi-ethnic country like Malaysia (Armeli et al., 2005). The awareness programme which includes public education, population screening, genetic counselling and antenatal diagnosis are among the support system that helps to increase the depth of understanding about this inherited disease.

The National Thalassaemia Prevention and Control Programme was endorsed by Malaysian Cabinet in 2004. There are 4 components to the programme which includes; increasing public awareness and health education, intensifying population screening and laboratory diagnosis, executing comprehensive management of patients, the thalassaemia registry and the cost implications or burden to the country (Ministry of Health Malaysia, 2012). In view of increasing knowledge on thalassaemia, continuous education needs to be applied. Public education is achieved by occasional reminders through the mass media (television or radio discussions, talks and documentaries) and frequent talks to smaller groups of school children and university students to enhance their knowledge and encourage thalassaemia carrier screening among these population. However, the difficulties in population screening as the prevention tool for this inherited disease has been the focus of discussion for decades (Modell et al., 1980). Doubts has been raised whether such programmes can provide promising results especially in increasing the awareness of the public regarding the disease. However, a study done among 3723 respondents in Malaysia in 2011 found that with better counselling, the knowledge and awareness will increase (Wong et al. 2011).

Such programmes especially in the prevention of β-homozygous thalassaemia has been operating in Cyprus since 1973. Since then, there has been an increasing gap between the number of homozygous born and the number expected (Angastiniotis and Hadjiminas, 1981). Small population size and well-informed public through education and counselling influence the reproductive behaviour of affected couples. Antenatal diagnosis also proved to play an important role in the reduction of homozygous thalassaemia birth in Cyprus (Angastiniotis and Hadjiminas, 1981).

Many are unaware that both parents must be a carrier to produce an affected child. For both parents who are confirmed to be carriers, there will be a 25% chance of having a normal baby, 50% chance of having a thalassaemia carrier baby and 25% chance of having a thalassaemic baby in every pregnancy. The Ministry of Health Malaysia has carried out a screening programme especially among teenagers. It is necessary to provide people with relevant information about thalassaemia in order to increase their awareness and knowledge. Rakhmilla *et al.* had demonstrated the effectiveness of video-show in illustrating the disease. The majority of the participants in the study expressed very positive attitude towards screening for thalassaemia (Rakhmilla et al., 2018). This is similar to MyHVP EduVariome Programme where interactive lectures were given by showing videos, infographics, pictures, exhibitions and quiz sessions. These activities had proven to significantly increase the knowledge and awareness among the students.

As the main point of this study was to show the effects of educational intervention on the knowledge score**,** the results of this study were in parallel with a recent study conducted in University of Malaya, Malaysia which found that lack of information to be the main cause of unawareness about thalassaemia in the community (Wong et al., 2011b). The current National Thalassaemia Prevention Programme in Malaysia is comprehensive and well executed, however with the execution of small scale programme such as the MyHVP EduVariome Programme, this may contribute to the increase in public awareness on thalassaemia in focused groups or even regional areas. It would be best if education intervention was given continuously to the secondary school students with various approaches such as interactive discussions, interesting thalassaemia related games, infographic information, setup of online games, impactful videos and pictures, creation of peer-buddy club among the students and other relevant approaches.

Conclusion

Education is one of the effective prevention strategies that have been agreed internationally. The forum-based lecture in the educational intervention programme done by MyHVP EduVariome had proven to increase the knowledge of the students regarding thalassaemia. Knowledge on the disease inheritance, signs and symptoms, and prevention steps needs to be conveyed to the public, and it needs to be delivered in an interesting approach in order to be impactful. By enhancing the public awareness of the disease, it will empower more people to volunteer, accept and support thalassaemia carrier screening programme carried out by the government to prevent thalassaemia child birth in the future.

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Appendix 1. List of schools and university participated in the EduVariome programme

No	Name of schools	Year	Town/ State
1	Sek. Men. Ahmad Maher, Kota Bharu	2014	Kota Bharu, Kelantan
2	Sek Men Sultan Ismali Petra	2014	Kota Bharu, Kelantan
3	Maktab Rendah Sains Mara	2015	Kota Bharu, Kelantan
4	Maktab Sultan Ismail (SIC)	2015	Kota Bharu, Kelantan
5	Sek Men Zainab	2015	Kota Bharu, Kelantan
6	Sek Men Beris Panchor	2015	Bachok, Kelantan
7	Sek Men Sains Faris Petra	2015	Kota Bharu, Kelantan
8	Sek Men Kuala Krai	2017	Kuala Krai, Kelantan
9	Sek Men Sultan Yahya Petra 1	2017	Kuala Krai, Kelantan
10	Sek Men Bandar Kuala Krai	2017	Kuala Krai, Kelantan
11	Sek Men Putera	2017	Kota Bharu, Kelantan
12	Sek Men Badang	2017	Kota Bharu, Kelantan
13	Sek Men Kota Bharu	2017	Kota Bharu, Kelantan
14	Sek Men Penambang	2017	Kota Bharu, Kelantan
15	Sek Men Zainab (2)	2017	Kota Bharu, Kelantan
16	Sek Men Puteri	2017	Kota Bharu, Kelantan
17	Sek Men Kedai Buloh	2017	Kota Bharu, Kelantan
18	Sek Men Tanjong Mas	2017	Kota Bharu, Kelantan
19	Sek Men Tanah Merah 1	2018	Tanah Merah, Kelantan
20	Sek Men Tanah Merah 2	2018	Tanah Merah, Kelantan
21	Sek Men Dato Mahmud Paduka Raja 1	2018	Tanah Merah, Kelantan
22	Sek Men Dato Mahmud Paduka Raja 2	2018	Tanah Merah, Kelantan
23	Sek Men Kebangsaan Machang	2018	Machang, Kelantan
24	Sek Men Kebangsaan Bandar Machang	2018	Machang, Kelantan
25	Sek Men kebangsaan Dato Biji Wangsa	2018	Machang, Kelantan