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

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\textbf{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.

\textbf{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.\textsuperscript{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.\textsuperscript{1} In South-east Asia, the prevalence of \textit{alpha-thal-1}, beta-thalassaemia and HbE gene is estimated to be 3-30%, 2-9%, and 10-50%, respectively.\textsuperscript{1} In Malaysia, the carrier rate was estimated to be 4.5% for the beta-thalassaemia gene\textsuperscript{1} and 3%-4% for HbE trait.\textsuperscript{1} 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)\textsuperscript{2} and in Malaysia, the cost is about RM3million (USD720,000) for the first 30 years of their lives.\textsuperscript{4}

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.\textsuperscript{1} 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