

Public perceptions and attitudes toward thalassaemia: Influencing factors in a multi-racial population.

Abstract

Background: Thalassaemia is a common public health problem in Malaysia and about 4.5 to 6% of the Malays and Chinese are carriers of this genetic disorder. The major forms of thalassaemia result in death in utero of affected foetuses (α -thalassaemia) or life-long blood transfusions for survival in β -thalassaemia. This study, the first nationwide population based survey of thalassaemia in Malaysia, aimed to determine differences in public awareness, perceptions and attitudes toward thalassaemia in the multi-racial population in Malaysia. Methods: A cross-sectional computer-assisted telephone interview survey of a representative sample of multi-racial Malaysians aged 18 years and above was conducted between July and December 2009. Results: Of a total of 3723 responding households, 2846 (76.4%) have heard of thalassaemia. Mean knowledge score was 11.85 (SD \pm 4.03), out of a maximum of 21, with higher scores indicating better knowledge. Statistically significant differences ($P < 0.05$) in total knowledge score by age groups, education attainment, employment status, and average household income were observed. Although the majority expressed very positive attitudes toward screening for thalassaemia, only 13.6% of married participants interviewed have been screened for thalassaemia. The majority (63.4%) were unsupportive of selective termination of foetuses diagnosed with thalassaemia major. Conclusion: Study shows that carrier and premarital screening programs for thalassaemia may be more effective and culturally acceptable in the reduction of pregnancies with thalassaemia major. The findings provide insights into culturally congruent educational interventions to reach out diverse socio-demographic and ethnic communities to increase knowledge and cultivate positive attitudes toward prevention of thalassaemia.

Keyword: Attitudes; Multi-racial population; Nationwide survey; Public awareness; Thalassaemia.