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Record 1 of 1**Title:** A single centre study on birth of children with transfusion-dependent thalassaemia in Malaysia and reasons for ineffective prevention**Author(s):** Ngim, CF (Ngim, C. F.); Ibrahim, H (Ibrahim, H.); Lai, NM (Lai, N. M.); Ng, CS (Ng, C. S.)**Source:** PRENATAL DIAGNOSIS **Volume:** 35 **Issue:** 1 **Pages:** 51-59 **DOI:** 10.1002/pd.4484 **Published:** JAN 2015**Times Cited in Web of Science Core Collection:** 1**Total Times Cited:** 1**Usage Count (Last 180 days):** 0**Usage Count (Since 2013):** 1**Cited Reference Count:** 28**Abstract:** Objective We aimed to identify factors contributing to ineffective prevention of thalassaemia in Malaysia by studying events leading to the births of children with transfusion-dependent thalassaemia (TDT) including their parents' reproductive choices.

Methods Thirty children with TDT born in the year 2005 to 2012 were included. Their parents underwent a semi-structured, face-to-face interview in 2012 and were followed up until 2014 to evaluate the actual decisions made during subsequent pregnancy.

Results In 70% of the cases (21/30), neither parent was aware of their carrier status until their child's diagnosis. Six of the remaining nine cases did not receive accurate information or support for prenatal diagnosis and the termination option. Of the 38 parents interviewed, 20 (52.6%) indicated that they would terminate an affected pregnancy. Notably, 52.2% of Muslims supported termination. Prenatal diagnosis was made in two of the five subsequent pregnancies, with thalassaemia traits diagnosed in both fetuses.

Conclusion The current poor uptake of voluntary thalassaemia screening in Malaysia and inadequate access to counselling and prenatal diagnostic services contributed to ineffective prevention. A considerable number of Malaysian Muslims may accept the termination option if given access to comprehensive genetic counselling services. (c) 2014 John Wiley & Sons, Ltd.

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