Reviewer’s report

Title: Public Perceptions and Attitudes towards Thalassaemia: Influencing factors in a Multi-racial Population

Version: 1 Date: 4 August 2010

Reviewer: Nadeem Qureshi

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Review of Public Perceptions and Attitudes towards Thalassaemia, Authors Li Ping Wong, J A Mary Anne Tan

I enjoyed reading this manuscript and suggest re-submission with appropriate amendments (major compulsory revisions).

Going through each specific sections:

INTRODUCTION
There was a good introduction to the size of the problem in Malaysia.

Major compulsory revisions:
• At the end of the section it would be useful to state more explicitly the objectives of the study (e.g. to identify the understanding about the condition)
• On page 4 “Control of pregnancies” please be more explicit what is meant by this.

METHODS
It is very impressive offering the structured interview in three languages in such a large cohort.

Major compulsory revisions:
• On page 5 it states, “If more than one eligible person is found in the household one person will be selected randomly” How was this done?
• For sample size what was the predicted prevalence measure (stated as +/- 2%) and what measure was assessed for this sample size.
• What was the design of the questions e.g. Likert scale/visual analogue scale.

Discretionary revisions:
• I assume there is a risk of selection bias as only individuals with phone access were sampled. Was there any socio-economic information on people who did not have phones? I note there is a brief comment about this in the discussion section.
• How was the survey instrument validated (at least for face validity)?
• How was it ensured that those who answered small red blood cells or shortage of blood (page 5-6) were thinking of thalassaemia as opposed to another cause e.g. iron deficiency anaemia?

RESULTS
There are several very interesting findings in the results, specifically:
• Misconceptions (page 9)
• Cultural differences in attitude and practice (page 10-11)
• In particular, the highly significant finding that nearly 23% state that they would be willing not to continue on with their partner if they were both carriers (page 11). In the discussion it would be worth considering these findings in relationship to other studies like this (e.g. Scrivers work in Montreal).

Major compulsory revisions:
It is important when performing multiple analyses that care is taken in interpreting findings. On page 8, Knowledge section, I would be careful commenting on the significance of several characteristics in table one.

Discretionary revisions:
• It would have been interesting to compare the responses between individuals who recognise a diagnosis of thalassaemia and those who specified a non-specific diagnosis (small blood cell/shortage of blood).
• Any information on 45% of sample that were non-responders. If there was no information on age or sex perhaps information on the locality of the phone (more likely not to respond if they have lived in a deprived area?).

DISCUSSION
The authors had a thoughtful description of the implications with respect to low educational status. They highlight the importance of improving the genetic health literacy of the population. Also on page 14 there is a good discussion of the public health implications of their findings.

Major compulsory revisions:
• Page 12. In the first paragraph, the principal findings is really dependent on the specified objectives. I would suggest that the findings related to attitude and practice (see my comments in the results section) are the most relevant. Further, description of mean scores as a principal finding is perhaps not that relevant, particularly considering this is not a validated instrument.
• On page 13, participants stating pre-marital screening as unnecessary is described as a concern. Please elaborate why this is a concern.
• In the final paragraph of page 13 the issue of termination of pregnancy is described. It would be useful to give some societal perspective on the acceptability of termination (e.g. forbidden by government legislation). The societal norms would impact on how individuals perceive termination.
• Limitations are described in some detail, but very limited information on the strengths of the study. I would suggest that having the participants complete a structured telephone interview is far more likely to have an appropriate completion rate than a self-administered survey.
• On page 16 the demographics of the participating population are described as similar to the general population. No data is provided to support this statement.

Discretionary revisions:
• On page 13 there was a good point about facilities for pre-marital and pre-natal diagnosis, but I am unclear how this comes out of the results.
• On page 15 the cross-sectional design is described as a limitation. I am not sure if this really is an issue when you are carrying out a knowledge and attitudinal survey.

ABSTRACT
A key point in the results is the nearly 14% of married participants that have not been screened. Also see comments in Results section.

Major compulsory revisions
At the end of the results section indications for carriers and premarital screening are described. Firstly, it is not appropriate to put this in the results section and secondly, I am not sure how this comes out of the results.

Discretionary revisions:
In the conclusions, educational interventions are suggested but this again is not mapped directly to the results of your study.

Level of interest: An article of importance in its field

Quality of written English: Acceptable

Statistical review: Yes, but I do not feel adequately qualified to assess the statistics.