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ORIGINAL ARTICLE

Attitudes towards prenatal diagnosis and abortion in a multi-ethnic country: a survey among parents of children with thalassaemia major in Malaysia

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Abstract Thalassaemia is a public health problem in multi-ethnic Malaysia which mainly affects the Malays, Kadazan-Dusuns and Chinese. This study, the first in Malaysia, aims to evaluate the acceptability of prenatal diagnosis and abortion among Malaysian parents who have a child or children with thalassaemia major and the socio-demographic factors affecting their decision-making. A pre-structured questionnaire was distributed to parents of children with thalassaemia major. Response rate for completed surveys was 99.1 %. Out of 116 respondents, the majority (83/71.6 %) were agreeable for prenatal diagnosis, but only 33 (28.4 %) agreed to both prenatal diagnosis followed by termination of affected foetuses. Of parents who declined abortion, 77.6 % cited religious restriction as the main reason, and their religious background was a significant factor (p=0.001), with 73.4 % of Muslim participants against termination compared to 25 % of Christians and 13.3 % of Buddhists. Gender, age, highest education level and number of children affected with thalassaemia were non-significant predictors in decision-making regarding abortion. The acceptance rate for termination of foetuses with thalassaemia major in Malaysia is low especially among the Muslims due to religious non-permissibility. Therefore, scholarly deliberations among the Malaysian Muslim religious authorities that result in a supportive stance in this issue may contribute to a more successful prevention programme.

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Introduction

The thalassaemias are recessively inherited disorders of haemoglobin synthesis common in people of Mediterranean, Middle East, Indian subcontinent and Asian origins. Thalassaemia is considered the most common genetic condition worldwide, and about 3 % of the world's population (approximately 150 million people) carry the β thalassaemia genes (Borgna-Pignatti and Galanello 2009). In Malaysia, approximately 4.5 % of the population are carriers of beta thalassaemia (George 2001), and 3–40 % are HbE carriers (Weatherall and Clegg 2001). Recent online data from the Malaysian Thalassaemia Registry as of September 2011 showed a total of 5,115 registered patients of which 2,207 have β thalassaemia major and 1,594 have HbE-β thalassaemia.

Patients with thalassaemia major require lifelong regular blood transfusions which necessitate burdensome and expensive chelation agents. In Malaysia, patients have free access to blood transfusions in government hospitals nationwide. From the year 2005, chelation agents in the form of subcutaneous deferoxamine and oral deferiprone are also offered free to patients. The newer oral chelator, deferasirox, will become accessible especially for the younger patients from the year 2012. The only curative option is by allogeneic haemopoietic stem cell transplant. In Malaysia, from the year 1987 to 2008, a total of 144 transplants were performed for haemoglobinopathies with an overall disease-free survival of 87.5 % (Teh and Chan 2008). However, the majority of Malaysian thalassaemia patients will still undergo treatment with regular blood transfusions and iron chelation in the form of subcutaneous deferoxamine. The huge economic and emotional burdens of

thalassaemia are important public health issues leading to the need for an effective prevention programme.

Many of the thalassaemia prevention programmes that were successful in various countries employed population screening, prenatal diagnosis and selective termination of pregnancy. Consequently, the birth rate of children born with thalassaemia major fell dramatically by 96 % in Cyprus (Kuliev 1986), 94 % in Sardinia (Cao et al. 1998) and 70 % in Iran (Samavat and Modell 2004; Christianson et al. 2004; Karimi et al. 2007) Those countries were, however, homogenous with regard to ethnic and religious composition, and employing similar preventive strategies in other countries and cultures may not yield equivalent success due to various dissimilar socio-cultural, religious, economic, technical and ethical perspectives. Additional factors may need to be accounted for in a multi-ethnic country such as Malaysia.

Malaysia has a multi-ethnic population of 28.3 million consisting of 50.1 % Malays, 22.6 % Chinese, 11.8 % indigenous peoples and 6.7 % Indians, and the remainder are non-citizens and minority groups (Department of Statistics Malaysia 2010). Data from the Department of Statistics in Malaysia also revealed the following—the Malays are all Muslims whereas 87 % of the Chinese population practises a mix of beliefs with influences from traditional Chinese religions such as Buddhism, Confucianism and Taoism, the majority of Indians (86 %) practise Hinduism and Christianity is embraced by 46 % of indigenous people especially those from the states of Sabah and Sarawak as well as 11 % of Chinese, 6 % of Indians and other minority groups.

Based on data from the Malaysian Thalassaemia Registry in 2009, the main ethnic background of Malaysian thalassaemia patients was recorded as Malay (62 %), Chinese (13 %) and Kadazan-Dusun (13 %). The Kadazan-Dusuns are the indigenous people of the state of Sabah. Compared to the background population demographics, thalassaemia appeared to affect more Kadazan-Dusuns and Malays compared to the Chinese and Indians (Table 1). This may be contributed by a higher prevalence of consanguineous marriages as well as carrier rates among the Kadazan-Dusuns where a recent study revealed carrier rates of 33.6 and 12.8 % for alpha and beta thalassaemia, respectively (Tan et al. 2010). About 4.5 % of Malays and Chinese are beta thalassaemia carriers (George 1998), but more Malays are affected by the homozygous states, and failure of preventive strategies among the Malays could have contributed to the ratio seen.

Table 1 Proportion of thalassaemia patients according to ethnicity compared to the general population in Malaysia, 2009 (source—Malaysian Thalassaemia Registry and Department of Statistics Malaysia)

Ethnic	% of thalassaemia patients	% of Malaysian population
Malay	62	50.4
Kadazan-Dusun	14	3.6
Chinese	13	23.7
Other indigenous ethnic groups (excluding Kadazan-Dusun)	10	15.2
Other minority ethnic groups		
Indians	1	7.1
Total	100	100

The success of preventive strategies depends largely on the acceptance of the targeted communities. Most of the successful thalassaemia preventive strategies incorporated prenatal diagnosis and selective termination of affected foetuses into their programmes. Studies addressing the acceptance of these measures have been done in Muslim-majority countries such as Iran (Karimi et al. 2010), Pakistan (Gilani et al. 2007), Lebanon (Zahed and Bou-dames 1997) and Saudi Arabia (Alkuraya and Kilani 2001) but are relatively scarce in Malaysia. A Malaysian survey among the general lay public documented not only a low level of knowledge about thalassaemia but it revealed that only 36.6 % of participants accepted selective termination of affected foetuses (Wong et al. 2011) with the Malays less likely to accept abortion compared to the Chinese and Indians. Although the reasons were not explored further, it was perceived that cultural and religious restrictions contributed to the Malay participants' rejection of abortion.

Our study addressed the attitudes of Malaysian parents who already have children affected by thalassaemia. These data represent the first such study in the country, and we hope it will provide insights that can contribute towards successful prevention in a multi-ethnic country.

Methodology

This cross-sectional study was conducted over 4 months (June to October 2011) in the state of Johor which has the fourth largest number of thalassaemia patients among the 14 states in Malaysia. As there were no published questionnaire surveys in this area, we conducted a focus group discussion with five parents of thalassaemic children to assist the development of survey items. A structured questionnaire using layman's terms was developed in English and then translated to Malay (Malaysia's national language) and Mandarin Chinese which is the commonest form of Chinese language used by the Malaysian Chinese. Each version of the questionnaire then underwent rigorous pilot testing before it was finalized. The self-administered questionnaires were then distributed to parents of children with thalassaemia major (which in our study was defined as thalassaemia diagnosed before the age of 2 and dependent on blood transfusions with a frequency of 2 monthly or less). Participation was voluntary, and all responses were

anonymous and returned in sealed envelopes to the attending staff that was also trained to clarify survey items should parents encounter difficulties comprehending them.

We used a convenience sample of parents attending the day-care centres in three major hospitals in Johor (Johor Bahru, Muar and Johor Jaya) as well as parents attending a state-level thalassaemia seminar organised in June 2011 in Johor Bahru, the state capital. Where both partners were approached, the questionnaires were administered separately.

Demographic details were recorded such as sex, age, religion, ethnic group, highest education attained and number of children with thalassaemia. As many Chinese practise a mixture of Buddhism, Taoism and Confucianism, this is categorised under "Buddhism", and Catholics were included in the "Christians" category. Each parent was asked if he/she was in favour of antenatal diagnosis at the early stage of pregnancy. Participants who favoured antenatal diagnosis were then asked if they would choose to terminate the pregnancy if the foetus was confirmed to have thalassaemia major at an early stage of pregnancy. Reasons for their responses to both items were further explored, where the participants were asked to choose the single most important reason out of a list of pre-defined choices. A space for free-text comments was also allocated if the reason was not among the pre-defined choices.

All the data were analysed using SPSS (PASW version 18, Chicago, IL, USA), and results were presented using descriptive statistics. We compared the responses of our participants using chi-square tests via cross-tabulation for categorical data or *t* test for independent groups for continuous data. This study was reviewed and approved by the Malaysian Ministry of Health Research and Ethics Committee and performed in accordance with the ethical standards in the 1964 Declaration of Helsinki.

Table 2 Participants' demographic details (n=116)

Gender[a]	Male, 41 (36.6 %)
	Female, 70 (60.3 %)
Ethnic group	Malay, 89 (76.7 %)
	Chinese, 20 (17.2 %)
	Indian, 2 (1.7 %)
	Others, 5 (4.3 %)
Religion	Muslim, 90 (76.9 %)
	Buddhist, 17 (14.5 %)
	Christian, 7 (6.0 %)
	Hindu, 2 (1.7 %)
Educational status[a]	Primary, 18 (16.4 %)
	Secondary, 73 (66.4 %)
	Diploma, 15 (13.6 %)
	University, 4 (3.6 %)
Age (years)	Mean, 40.4 (SD, 7.7)
Number of affected children[a]	Mean, 1.3 (SD, 0.5)
	One, 77 (71.3 %)
	Two, 29 (26.9 %)
	Three, 2 (1.9 %)
Religion according to ethnicity	Malay:
	•Muslim, 89 (100 %)
	Chinese:
	•Buddhist, 17 (85.0 %)
	•Christian, 2 (10.0 %)
	•Muslim, 1 (5.0 %)
	Indian:
	•Hindu, 2 (100 %)

[a] The total response is less than 116 due to missing data

Results

All 117 parents approached agreed to participate in the survey. One participant did not respond to questions on antenatal diagnosis and termination of pregnancy and was excluded from the analysis; thus, we achieved a 99.1 % response rate of completed surveys. The demographic details of the participants are depicted in Table 2. Out of 116 parents who completed the survey, 83 (71.6 %) were in favour of antenatal diagnosis. No significant factors were associated with a preference for antenatal diagnosis (Table 3). The 33 (28.4 %) who declined antenatal diagnosis gave the main reasons as "condition not serious enough to warrant a termination of pregnancy" (35.5 %), "emotional reasons" (25.8 %) and "termination of pregnancy is forbidden by my religion" (19.4 %) (Table 5).

Out of 83 parents who were in favour of antenatal diagnosis, only 33 (39.8 %) were agreeable to terminate a pregnancy carrying a foetus with thalassaemia major (Table 4). For the remainder 50 (60.2 %) respondents who declined, "termination of pregnancy is forbidden by my religion" (77.6 %), "condition not serious enough to warrant a termination of pregnancy" (14.3 %) and "emotional reason" (6.1 %) were the main reasons given (Table 5). Out of the 38 parents who refused to terminate the pregnancy based on religious grounds, 36 were Malay Muslims and the remainder 2 participants were Chinese (one Buddhist and one Christian).

Religion was significantly associated with a decision to terminate an affected pregnancy among parents who agreed for antenatal diagnosis (p=0.001), with 73.4 % of Muslim participants against termination compared to 25 % of Christians and 13.3 % of Buddhists (Table 4). Comparing different ethnic groups, a greater proportion of Malays (73 %) compared to Chinese (22.2 %) declined termination (p<0.001). There were no difference among the respondents who were in favour of termination versus those who were against termination in terms of gender, age, highest education level and number of children affected with thalassaemia (Table 4).

Table 3 Socio-demographic differences in decision-making regarding prenatal diagnosis

		Agreeable for prenatal diagnosis		
		Yes, *n* (%)	No, *n* (%)	*p* value
Total	116 (100)	83 (71.6)	33 (28.4)	
Gender	Male	29 (72.5)	11 (27.5)	0.6
	Female	49 (69.0)	22 (31.0)	
	No data	5		
Ethnic group	Malay	63 (71.6)	25 (28.4)	0.2*
	Chinese	18 (90.0)	2 (10.0)	
	Indian	0 (0)	2 (100)	
	Others	2 (40)	3 (60)	
Religion	Muslim	64 (71.9)	25 (28.1)	0.8*
	Buddhist	15 (88.2)	2 (11.8)	
	Christian	4 (50.0)	4 (50.0)	
	Hindu	0 (0)	2 (100)	
Educational status	Primary	14 (82.4)	3 (17.6)	0.6*
	Secondary	49 (67.1)	24 (32.9)	
	Diploma	12 (80.0)	3 (20.0)	
	University	2 (50.0)	2 (50.0)	
	No data	6	1	
Age	Mean±SD (years)	40.9±7.4	39.2±8.5	0.8
Number of affected children	Mean±SD	1.30±0.49	1.29±0.53	0.8

*p values presented here are based on comparisons across multiple groups

Discussion

In a cross-sectional survey among 3,723 members of the general public in Malaysia (Wong et al. 2011), only 36.6 % were supportive of selective termination of foetuses diagnosed with thalassaemia major. As these households have no affected children, many may assume that parents with thalassaemic children will be more inclined to terminate affected pregnancies having personally raised a thalassaemic child which leads to greater awareness of the suffering that this condition can

Table 4 Socio-demographic differences regarding termination of pregnancies affected by thalassaemia major

		Agreeable for termination of pregnancy		
		Yes, *n* (%)	No, *n* (%)	*p* value
Total	83 (100)	33 (39.8)	50 (60.2)	
Gender	Male	12 (41.4)	17 (58.6)	0.5
	Female	19 (38.8)	30 (61.2)	
	No data	2	3	
Ethnic group	Malay	17 (27.0)	46 (73.0)	< 0.001*
	Chinese	14 (77.8)	4 (22.2 %)	
	Indian	Not applicable		
	Others	2 (100)	0 (0)	
Religion	Muslim	17 (26.6)	47 (73.4)	0.001*
	Buddhist	13 (86.7)	2 (13.3 %)	
	Christian	3 (75.0)	1 (25.0)	
	Hindu	Not applicable		
Educational status	Primary	6 (42.9)	8 (57.1)	0.7*
	Secondary	20 (40.8)	29 (59.2)	
	Diploma	6 (50.0)	6 (50.0)	
	University	0 (0)	2 (100)	
	Missing data	1	5	
Age (years)	Mean±SD	40.3±7.1	41.3±7.6	0.8
Number of affected children	Mean±SD	1.10±0.30	1.43±0.54	0.2

*p values presented here are based on comparisons across multiple groups

Table 5 Reasons cited for declining antenatal diagnosis and termination of pregnancy carrying a foetus affected by thalassaemia major

Reasons	Participants declining antenatal diagnosis (n=33)		Participants declining termination of pregnancy affected by thalassaemia major (n=50)	
	n	%	n	%
Not allowed by religion	6	19.4	38 (36 Muslims, 1 Buddhist, 1 Christian)	77.6
Emotional	8	25.8	3	6.1
Condition not serious enough	11	35.5	7	14.3
Difficulty in accessing this service	5	16.1	0	0
Others	1	3.2	1	2.0

cause. In our study of 116 parents of thalassaemic children, although the majority (71.6 %) of participants favour antenatal diagnosis, only 33 (28.4 %) were willing to undergo both antenatal diagnosis followed by termination of affected foetuses. This finding is similar to that of a study by Ahmed et al. (2006) where most women wanted prenatal diagnosis as they wish to know their child's condition, but they did not necessarily agree to the termination of affected foetuses.

In our study, religious consideration was the main reason offered for declining selective abortion (p=0.001), and this mainly affects the Malays who are all Muslims. In Malaysia, the Muslims' family and religious practices are guided by authorities like the National Council of Islamic Religious Affairs which oversees religious decrees at the national level. However, in states where there are reigning sultans, religious affairs by legislature are under the purview of the various state Islamic religious councils. The national council decrees are legally non-binding and serve as guidance to be adopted upon consent of the sultan. In relation to thalassaemia, the Fatwa Committee, at the Council's 52nd Muzakarah (Conference) in July 2002 has decreed that "termination of pregnancy before 120 days is permissible if the foetus is disfigured, ill and can harm the life of the mother". As a foetus affected with thalassaemia major does not fully qualify the above prerequisites, this affects the Malay Muslims' full acceptance of termination of thalassaemic foetuses.

With regard to the Islamic stance on termination of a foetus with a serious disorder, a number of Islamic countries like Kuwait and Saudi Arabia have ruled that termination is permissible before ensoulment at 120 days of gestation (Ahmed et al. 2006). In Pakistan, two renowned Islamic scholars ruled that a pregnancy can be terminated if the foetus is affected by a serious genetic disorder and if termination is before 120 days (17 weeks) of gestation (Ahmed et al. 2000). In Iran, abortion was illegal when pre-marital screening was first introduced, but based on systematic feedback by the population screened, intensive and widespread ethical discussions were held which led to a Fatwa issued in 1998 which allowed pregnancy termination up to 16 weeks for some genetic disabling disorders including beta thalassaemia (Samavat and Modell 2004). Most of the religious edicts do not permit abortion after 120 days unless the mother's life is harmed.

Muslims are committed to comply with religious teachings, and religious permissibility in these countries has led to acceptance of antenatal diagnosis and termination of thalassaemic foetuses. The acceptance rate was 90.3 % in Iran (Karimi et al. 2010) and 75.2 % in Pakistan (Gilani et al. 2007). Recent studies on Muslim populations revealed that education about the religion's stance on termination of pregnancy improved uptake of prenatal diagnosis and termination of pregnancies affected by thalassaemia and sickle cell anaemia (Alkuraya and Kilani 2001; Ahmed et al. 2000). For example, in Saudi Arabia, Alkuraya and Kilani (2001) found that 28 out of 32 Muslim participants refused abortion, but 13 (46.4 %) changed their minds after they were given the Fatwa on abortion. In Egypt, where previously there was a poor uptake of termination among pregnant mothers with affected foetuses, a recent study showed that with comprehensive in-depth counselling addressing the Islamic aspects of termination, uptake of selective abortion increased significantly (El-Beshlawy et al. 2012). These studies highlight the importance of religious permissibility as well as education of the target population to enable a successful prevention programme. Besides religious teachings, other factors which may affect a Muslim woman's decision on abortion are the perceived severity of the disease and family support (Ahmed et al. 2006).

In our study, 86.7 % of the Chinese in Malaysia accepted termination. Most of the Malaysian Chinese practise a mixture of Buddhism, Taoism and Confucianism, and a smaller minority embraces Christianity. The lack of strict religious guidelines on abortion issues, less compulsion to follow religious guidelines within the community as well as a more pragmatic approach in life most likely led to the higher acceptance rate of abortion. As for the Christians who made up 6.8 % of our study population, 25 % were against termination, and those who were Roman Catholics appeared to decline abortion as this is forbidden among them.

In our cohort of 116 parents, 33 parents have declined prenatal diagnosis, and the most cited reason was that "the condition is not serious enough". Even amongst parents who

accepted antenatal diagnosis but declined abortion, this was the second most cited reason after religious restrictions. This viewpoint reflects the improvement in the Malaysian health care services for patients with thalassaemia. Prior to 2005, patients were only provided with free access to blood transfusions, and the majority of them succumbed to severe iron overload in their teens. However, since 2005, the government provides free iron chelation, and survival rates together with quality of life have improved leading parents to view that thalassaemia is not a "serious condition". We did not study the age of the affected children amongst parents surveyed, but most of the children were likely to be relatively young as the mean age of their parents in the survey was only 40.4 years old. As most complications tended to set in during adolescence or adulthood, parents of these young children might have regarded thalassaemia major as a "condition not serious enough to warrant abortion". It is likely that these parents have not been adequately informed of the long-term complications, management and the effects on quality of life of this condition; hence, the importance of providing this information during counselling sessions to at-risk couples should be emphasized in the future

Since year 2005, the Malaysian Ministry of Health has launched a national programme to prevent and control thalassaemia nationwide. Best possible care in the form of free iron chelation as well as public awareness and health education campaigns are carried out. Screening, however, is offered only to interested parties who present to the medical facilities on a voluntary basis, and pre-marital carrier screening in general is still not mandatory. After an affected child is diagnosed, retrospective genetic counselling is offered as well as cascade screening to relatives. Prenatal diagnosis and termination of pregnancy for thalassaemia is available since 20 years ago in Malaysia (Ainoon and Cheong 1994). This approach which has led to successful prevention in many countries has yet to be actively incorporated into our Malaysian national programme partly due to the current conservative and cautious stand on abortion by the consensus decision of the Fatwa council members. However, as exemplified in other Muslim countries and precedents from other medical-related decrees, the consensus opinion may change to accommodate new evidences or other mitigating circumstances that would allow termination of pregnancy in selected cases. Pre-implantation genetic diagnosis which may be more acceptable is still not feasible due to financial and technical reasons.

We recognise the following strength and limitations in our study. The high response rate we achieved to our survey was most likely due to the convenience sample gathered in a single sitting, the anonymous manner in which it was conducted as well as the items which were concise and easily understood by our participants who received at least a primary school education. As the survey was conducted in settings (thalassaemia day-care centre and seminar) where their children's health care providers were present, the parents may have been compelled to accede to the request to participate in the survey. Furthermore, in such settings, participants' responses might be biassed towards giving socially desirable responses despite the anonymised nature of our survey. For instance, the opinions on prenatal diagnosis and abortion might have been skewed towards what they perceived the health care providers were in favour of. When exploring the reasons parents chose a certain reproductive option, we provided pre-defined choices and limited the response to a single selection. This approach was useful in standardizing responses, but it might not have encompassed the breadth and depth of possible responses which might be obtained had we chosen to explore this in focus group discussions. Further clarification should have been sought for parents who chose "emotional reasons" so that their values, beliefs or feelings could be identified. We used "early stage of pregnancy" in our survey without specifying the gestational age, and this might have led to some uncertainties in the participants' responses. Additionally, our study was conducted in the day-care centres of three referral hospitals where two thirds of the patients in Johor state sought treatment as well as among parents who attended a thalassaemia seminar in the state capital. Therefore, parents staying in the smaller districts or those who lacked the motivation or opportunity to attend the seminar may be under-represented. Lastly, the findings in the state of Johor cannot be generalised to the Borneo state of Sabah which carries the highest burden of thalassaemia among all the states in Malaysia. Most of the Sabahan patients are from the Kadazan-Dusun ethnic group where a sizeable proportion of them are Catholics who may reject abortion for thalassaemia major based on religious restrictions.

Conclusion

This study highlighted a number of important observations with far-reaching implications for the prevention of thalassaemia in a multi-ethnic country. We have shown that even among parents of children with thalassaemia major, there is a low acceptance rate for prenatal diagnosis and termination of affected pregnancies. Acceptance rates for abortion vary markedly depending on the ethnic and religious backgrounds where perceived religious non-permissibility is an important factor leading to a high rate of non-acceptance among the Malay Muslims. In a country with such a diverse cultural background and religious beliefs like Malaysia, it is essential for us to understand the issues in depth so that we can implement effective strategies towards successful prevention. This study suggests that scholarly deliberations among the Malaysian Muslim religious authorities that result in a supportive stance

in prenatal diagnosis and selective abortion may contribute to a more successful prevention programme, but this issue should be approached with a lot of tact and sensitivity. Besides that, education should be improved among parents with affected children, and this should include adequate information on the long-term morbidity and mortality associated with thalassaemia. They can thus acquire a balanced viewpoint, and an informed decision may then be made with regard to their reproductive options.

Our survey seeks to address the views of thalassaemia carriers, although their views might not necessarily translate accurately into actual behaviours. We therefore suggest that future studies should employ a more objective approach by observing and reporting the actual choices made by participants when offered genetic counselling and prenatal diagnosis.

Last but not the least, the health authorities will need to explore various other strategies such as public education, an effective national screening programme as well as the accessibility of counselling, genetic and antenatal services so as to ensure an effective prevention programme which will be sustainable in the long run.

Conflict of interest The authors declare that they have no conflict of interest.

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