J Community Genet (2011) 2:71–79
DOI 10.1007/s12687-011-0039-z

ORIGINAL ARTICLE

A holistic approach to education programs in thalassemia for a multi-ethnic population: consideration of perspectives, attitudes, and perceived needs

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Received: 17 August 2010 / Accepted: 3 February 2011 / Published online: 24 February 2011

Abstract Hemoglobin disorders which include thalassemias are the most common heritable disorders. Effective treatment is available, and these disorders can be avoided as identification of carriers is achievable using simple hematological tests. An in-depth understanding of the awareness, attitudes, perceptions, and screening reservations towards thalassemia is necessary, as Malaysia has a multi-ethnic population with different religious beliefs. A total of 13 focus group discussions (70 participants) with members of the general lay public were conducted between November 2008 and January 2009. Lack of knowledge and understanding about thalassemia leads to general confusions over differences between thalassemia carriers and thalassemia major, inheritance patterns, and the physical and psychologically impact of the disorder in affected individuals and their families. Although most of the participants have not been tested for thalassemia, a large majority expressed willingness to be screened. Views on prenatal diagnosis and termination of fetuses with thalassemia major received mixed opinions from participants with different religions and practices. Perceived stigma and discrimination attached to being a carrier emerged as a vital topic in some group discussions where disparity in the answers exhibited differences in levels of participants' literacy and ethnic origins. The two most common needs identified from the discussion were information and screening facilities. Participants' interest in knowing the severity of the disease and assessing their risk of getting the disorder may imply the health belief model as a possible means of predicting thalassemia public screening services. Findings provide valuable insights for the development of more effective educational, screening, and prenatal diagnostic services in the multi-ethnic Asian society.

Keywords Thalassemia · Education programs · Multi-ethnic population · Perspectives · Attitudes · Needs

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Introduction

Hemoglobinopathies are blood disorders with an estimated 270 million individuals who are carriers of globin gene mutations (Weatherall 2005). Thalassemia results in a reduction or absence in globin chain synthesis and is a public health problem in Malaysia (Teh et al. 2009). Beta thalassemia major causes severe anemia that requires lifelong transfusions together with daily iron chelation therapies for survival. The treatments are expensive, an economic burden to the country, and a drain on pediatric

services. In α-thalassemia, the most severe form results in death in utero and maternal complications include placentomegaly and hypertension. Alpha and β-thalassemia together with a few hemoglobin variants (Hemoglobin E, Hemoglobin Constant Spring, Hemoglobin Quong Sze) have been detected in the Malays, Chinese, and indigenous populations in Malaysia (George 1998; Tan et al. 2006; Wee et al. 2009).

Much evidence indicates the negative impact on the mental and psychological well-being of thalassemia major patients. In the medical model of disability, prenatal diagnosis and termination of pregnancy resulted in reduced prevalence of this disorder and societal burden. In contrast, according to the social model of disability, disability is viewed as a reflection of societal attitudes and the environment they live in. Therefore, there has been a considerable debate and controversy regarding termination of pregnancy if genetic testing identified a genetic disorder in the fetus in the context of socially constructs disability. Nevertheless, thalassemia major patients are able to live a normal lifespan with good coping strategies that entail individual personal and collective efforts of family, society, material resources, and health services (Atkin and Ahmad 2001). However, management and treatment of thalassemia major has deleterious economic consequences to the country. In Malaysia, all thalassemia major patients have access to desferrioxamine iron chelating treatment. With the total number of 4,768 transfusion-dependent thalassemia patients in the National Thalassemia Registry as of May 2010, and with an approximate cost of US $294–882 for iron chelation per patient per month, clinical management of thalassemia major in our country imposes a remarkable economic burden to the health system.

Currently, premarital screening for thalassemia carrier is not compulsory in Malaysia. In most cases, thalassemia carriers were identified during antenatal screening, given genetic counseling and fetal diagnosis. The decision of not having thalassemia child in Malaysia is entirely up to individual's decision and is conformed to cultural and religious practices of the respective ethic groups. Malaysia is a multi-ethnic country, with a population of 27.7 million and is made up of a Malay majority (50.8%) together with other ethnic groups, mainly Chinese (23.0%), indigenous people of Sabah and Sarawak (11.0%), and Indians (6.9%). Other minority groups make up the remaining 8.3% of the population (Social Statistics Bulletin 2008). As a result of this multi-ethnic population, Malaysians follow different religious faiths—Islam, Buddhism, Taoism, Confucianism, Christianity, Hinduism, and Sikhism.

Social, cultural, and religious issues are closely intertwined with thalassemia in many developing countries in Asia. In India, a thalassemia carrier is socially isolated with lower marital prospects (Saxena and Phadke 2002; Chattopadhyay 2006). It has been reported that attitudes toward termination of fetuses with thalassemia major were associated with religious practices, particularly among Muslims where prenatal diagnosis is often refused on religious grounds (Zahed and Bou-Dames 1997; Ahmed et al. 2006a). A lack of knowledge about the disorder, its manifestations, survival rate, treatment availability, and psychosocial and cultural issues may cause barriers to optimal health care including disclosure of thalassemia status as well as to carrier testing (Chattopadhyay 2006). It has been empirical proven that community-wide education programs dramatically increase population awareness of thalassemia and reduce the number of children born with thalassemia major (Angastiniotis et al. 1986; Gill and Modell 1988; Ahmed et al. 2002; Samavat and Modell 2004). Religious teachings have also notably affected individuals' attitudes towards accepting prenatal diagnosis and termination of affected pregnancies (Alkuraya and Kilani 2001; Samavat and Modell 2004). Holistic approaches that include culturally sensitive and acceptable strategies, in addition to public education, have worked best in developing countries with a rich cultural and religious heritage (Alkuraya and Kilani 2001; Ahmed et al. 2002; Samavat and Modell 2004).

Qualitative studies on thalassemia have not been carried out in Malaysia. As a result, there is little in-depth understanding of the attitudes, perceptions, and carrier screening reservations of thalassemia in our diverse and multi-ethnic population. In addition, thalassemia-related needs have never been studied. This paper aims to address the gaps. An understanding of the population's knowledge, attitudes, fear of discrimination, and religious restrictions is fundamental to the provision of successful education and effective carrier screening and prenatal diagnostic services that will meet the requirements of a multi-ethnic society.

Methods

A qualitative method was used to gather information of participants' knowledge, attitudes and needs related to thalassemia. A convenient sample of participants from the general lay public aged 18–55 years was recruited in the Klang Valley area of Malaysia. The focus group discussions (FGDs) were held between November 2008 to January 2009 at locations and times convenient to the participants. The focus groups were conducted in the community settings and at sites that were convenient for each group such as participants' home or office. The FGDs were divided into the three main ethnic groups—Malays, Chinese, and Indians—and according to different levels of education to ensure homogeneity, thus allowing participants to feel at ease in expressing themselves. The division of participants into specific ethnic groups

also allowed comparison of findings across the groups with different cultural and religious backgrounds. Before each FGD, a written questionnaire was completed by participants to gather information about their demographic backgrounds. Group discussions were conducted in English, Bahasa Malaysia (Malaysia's national language), or the respondents' native language (Cantonese and Mandarin). Written informed consent was obtained from all participants.

A semi-structure focus group moderator's guide corresponding to the research questions was developed. The guide consisted of four sections. The first part obtained participants' general knowledge and awareness about thalassemia. Subsequently, the moderator read a brief excerpt about thalassemia and showed an illustration about the inheritance patterns at each session before proceeding to discussion about attitudes and perception of thalassemia. Throughout the focus group discussions, the term "thalassemia" refers to the homozygous form of the disease or thalassemia major. The term "thalassemia carrier" refers to the carrier state for thalassemia major.

The following is an excerpt that was read out to all the focus groups,

> Thalassemia is a disease with low numbers of red blood cells or shortage of blood. Thalassemia is an inherited blood disorder, and an approximately 4–5% of the Malaysian population are carriers of thalassemia. The two main types of thalassemia are called alpha and beta thalassemia. When two individuals with the same thalassemia trait have children, for each pregnancy there is a 25% chance of having a child with a severe form of the disorder. There is a 50% (2 in 4) chance that the child will inherit one normal and one mutant gene (a carrier of the disease) and have the trait like the parents; and a 25% (1 in 4) chance that the child will be completely free of the disease (normal).

For each pregnancy, there is a 25% chance of having an unaffected child,

The second part queried participants about their attitudes towards premarital screening, prenatal diagnosis, and termination of pregnancy, stigma, and discrimination associated with thalassemia. The last section discussed about the needs of participants. The guide was pilot-tested and revised, and final revision remains the same for all the focus groups. Discussions were conducted for approximately 1 h, digitally recorded, and transcribed into English. The sampling process, data collection, and analysis were continuous and iterative. All conducted discussions were immediately analyzed and compared with the analysis of the previous discussions, which, in turn, further shaped the subsequent sampling, data collection, and analysis. The FGDs were continued until data saturation was reached or no new information was uncovered. Coding and categorizing was carried out using the QSR NVivo qualitative computer software program. Transcripts were thematically coded according to the research themes that emerged from the discussions, and the themes were then sorted into subthemes. This study was approved by the Medical Ethics Committee, University Malaya Medical Center, Kuala Lumpur, Malaysia.

Results

Participants

Participants were recruited from multiple sources and through a variety of strategies (snowballing and peer referral) from urban and suburban areas in Klang Valley of Malaysia. A total of 13 FGDs—four Malay, five Chinese, and four Indian groups were conducted. Each FGDs composed of five to eight participants of the same ethnic group (total 70 participants). The mean age of the sample was 36.4 years (SD±12.2). The demographic distribution of the study sample is shown on Table 1. The main themes and illustrative quotes are displayed in Table 2.

Knowledge and awareness

Only 68.6% (48/70) of participants had heard of thalassemia before the excerpt was read. Six of the participants (8.6%) had family members who were thalassemia carriers or affected with thalassemia major. Friends (31.4%), mass media (18.6%), health carers (8.6%), and schools (5.7%) were the main sources of information. Across the group discussions, the vast majority of participants, even among those that had heard of thalassemia, were unable to give a correct definition of the disorder. Although some of the participants correctly define thalassemia as an inherited blood disorders, there were erroneous beliefs that thalassemia is a blood cancer. When asked how a person acquires thalassemia, the majority were aware that thalassemia is genetically acquired. When probed further as to whether thalassemia is also a communicable disease and can be transmitted from one person to another, some participants, majority from lower levels of educational achievement, were unsure. Most participants did not know the incidence of thalassemia in Malaysia as nearly half of the participants perceived thalassemia as *very rare*, *not serious*, or *not a common disease*.

Almost all groups perceived a lack of information to be the main cause of unawareness about thalassemia in the general public. Some pointed out that educational material were lacking in public places and health care centers. Some

Table 1 Demographic characteristics of respondents (N=70)

Socio-demographic variables	Total sample	
	N	%
Gender		
Male	27	38.6
Female	43	61.4
Marital status		
Single	23	32.9
Married	47	67.1
Ethnicity		
Malay	22	31.4
Chinese	28	40.0
Indian	19	27.1
Others	1	1.4
Age		
<30	27	38.6
30–40	12	17.1
41–50	21	30.0
>50	10	14.3
Highest education attainment		
Low education		
Primary school	5	7.1
Secondary school	30	42.9
High education		
University	35	50.0
Occupation		
Professional	13	18.6
Managerial	17	24.3
Skilled workers	19	27.1
Unemployed and retired	12	17.1
Housewife	9	12.9
Average monthly household income[a,b]		
<2,000	23	35.9
2,001–4,000	22	34.4
>4,001	19	29.7
Locality		
Urban and suburban	61	87.1
Rural	9	12.9

[a] The national average monthly household income in Malaysian Ringgit (RM) is RM3,686 (US $1=RM3.24, as of April 2, 2010). Source: Mid-term review of the Ninth Malaysia Plan 2006–2010, Economic Planning Unit (EPU), Prime Minister's Department, 2008

[b] Number of respondents less than 70 (total respondent) due to non-response

focus group participants made several suggestions, including dissemination of educational materials in the form of posters and pamphlets at public places such as shopping malls, markets, worship centers (churches and temples), and in marriage registries.

There was confusion between thalassemia major and carrier across all groups as participants were not able to tell the difference. The most commonly cited symptoms of thalassemia major were pale skin, lack of blood, tiredness, and protruding abdomen. There were incorrect assumptions that all thalassemia major children are mentally retarded, physically abnormal, bedridden, and unable to carry out daily activities or attend school. Some even believed that thalassemia carriers also exhibit similar symptoms and required blood transfusions. The majority of participants were unaware that there are different types of thalassemias and that α- and β-thalassemia are the two most common. Knowledge about the genetics of thalassemia was also very poor. Many were unaware that both parents must be carriers in order to produce an affected child and that carrier parents have a chance of 1:2:1 of having children who are normal, carrier, and thalassemia major. Across all FGDs, it was frequently misperceived that only one parent has to be a carrier to produce affected children. Owing to the genetic complexity of the disease, a majority of participants, especially individuals of low literacy, asked for educational material in layman's terms. The Malay groups specifically desired accurate information about *fatwa* regarding prenatal diagnosis and abortion of fetuses with thalassemia major. These groups unanimously agreed they would follow the teachings and views of local religious leaders with regards to termination of affected pregnancies.

Attitudes

This study detected a high acceptability for premarital screening for thalassemia. The main reason as to why Malaysians do not undergo screening is a lack of awareness and limited availability of information about the disorder, rather than unwillingness to undergo the test. Many were also supportive of mandatory premarital screening for thalassemia. Some participants felt that they may become depressed, resentful, or embarrassed in the event of a positive test result and a few expressed genuine concerns regarding partner's reaction if they were confirmed to be carriers. Thus, participants felt that it would be more fitting for carrier screening to start in secondary school (13–17 years).

There were mixed views regarding termination of pregnancies with thalassemia major. Across all group discussions, regardless of participants' religious faiths, the majority of men and women regard all forms of abortions, including abortion of fetuses with thalassemia major as unethical. Other reasons against the abortion of such fetuses were the right to live, health consequences of abortion, and that advances in medicine will offer new treatment or cures. However, in some instances, there were changes in the attitudes toward termination of pregnancy after the moderator unanimously brought up concerns related to the

Table 2 Summary of themes and quotes

Themes	Participant quotations
1. Knowledge and awareness	
General knowledge	*I only know thalassemia is something related to blood but I don't know exactly what it is.* 33 Indian male, secondary education *I just know the name thalasseamia, a sickness, but I don't know the symptoms, or how it is transmitted, or the symptoms*. 21 Indian female, tertiary education
	People affected with thalassemia maybe mentally retarded, effect the brain, cannot talk, abnormal. 21 Indian female, tertiary education *thalassemia major is the advance level, possibly lethal. Minor is the early stage, can still be cured.* 39 Malay female, tertiary education
Prevalence and severity	*I think it is rare, because I hardly heard of it. Unlike HIV, we often heard of HIV over the media, this means it is serious.* 21 Chinese female, tertiary education
	I think recently it becomes very serious, because of the advertisement.
	When there is a campaign like that, it means serious. 45 Malay female, secondary education
2. Attitudes	
Premarital screening	*Definitely before marriage I would do the test.* 24 Indian male, tertiary education.
	Should be screened at school level, before marriage couples are busy many wedding or marriage preparations. 23 Malay female, tertiary education
	Premarital is too late, before courtship they should be screened, should know they own record…hard to prevent marriages at that stage. 30
	Indian female, tertiary education.
Prenatal diagnosis and termination of pregnancy	*Not only because of religion, it is bad for the woman's health to undergo abortion. You are conceiving a life, not good to abort babies.* 43 Chinese female, secondary education
	I think under 4 months can be aborted, otherwise should bring the baby to life. 51 Malay female, tertiary education
	Let it (thalassemia major baby) *be born, abortion is against Islam, have to see the stand of the Islam on abortion, we must clearly know whether this is against our religion.* 26 Malay male, tertiary education
Perceived prejudice and discrimination	*I think I will only disclose to my family, close family members only.* 21 Indian female, tertiary education
	If possible, I don't want in-law like this (thalassemia carrier). *I don't want my children or grandchildren affected. Have to know early, and don't let them date, or become too close.* 45 Malay female, secondary education
3. Screening behaviors	
Carrier screening for thalassemia	*I have never thought of doing the test, because it is not common.* 35 Indian male, tertiary education
	We don't know much about the disease, never thought of screening. 32 Indian female, tertiary education
4. Needs	
Information needs	*Information regarding consequences of thalassemia that can actually trigger …that you should go for screening.* 21 Indian female, tertiary education.
	It is very common in our country? How many percent carrier in our country? If high percentage we should check ourselves. 21 Chinese female, tertiary education
	If want to abort the child, only if the fatwa allow, otherwise the couple have to bear, so have to depend for fatwa. 45 Malay female, secondary

physical and psychological impact of thalassemia major on patients and their families, including lifelong blood transfusion, frequent visits to hospital, and negative impact incurred from iron chelation therapy on activities of daily living. Although being informed that despite these profound impacts thalassemia major patients can live long lives if they have access to proper treatment, many participants still feel that the burden of long-term physical and psychological impacts is almost unbearable. Participants who have encountered or knew an affected individual were more likely to support termination of pregnancies. The Chinese and Indian groups were more likely to accept abortion of affected fetuses. Malay Muslim participants viewed abortion to be permissible only when a continuing pregnancy endangers the mother's life. Thus, they regard termination of affected pregnancies with thalassemia major, where the life of the mother is not endangered, as sinful and *haram* (forbidden). There were also a considerable number of Muslim participants who admitted that they were uninformed of Islam's perspective on termination of abnormal fetuses. Some responded that abortion is permissible below 4 months gestation as after this period, the fetus is thought to become a living soul. Despite unfavorable views on termination of pregnancies with thalassemia

major, most of the participants across all discussion groups regardless of ethnicity and educational levels were supportive of compulsory prenatal diagnosis.

When participants were asked regarding willingness to publicly disclose if they were carriers, the majority of the participants were more likely to refuse disclosure. The common reasons were fear of prejudice and discrimination. A substantial number of participants viewed that families with thalassemia major would be discriminated and men were less likely to seek marriage with these families. These conservative views were more prevalent among the Indians regardless of educational levels. Several young women, regardless of ethnic groups, perceived that if they are thalassemia carrier, their parents would not approve their marriage with someone who is also a carrier.

Among the middle age and older participants, unwillingness to allow their children to marry a thalassemia carrier was expressed in a few Malay groups of relatively lower level of literacy, albeit in the minority. The Chinese were the least concerned about this and viewed that the younger generation should be left to make their decisions. In general, younger participants with higher levels of education were more open-minded and expressed less prejudice and discrimination with regards to marrying individuals with thalassemia.

Screening behaviors

The majority of participants have never been tested for thalassemia, the reasons being unawareness or if they were aware, they simply did not consider doing the test. Nevertheless, most were positive about the benefits of testing and indicated their willingness to be tested. Unmarried participants expressed willingness to undergo thalassemia screening for themselves and their partners before marriage. However, a small minority refused to be tested for fear of a positive result that may result to social exclusion. With regard to prenatal diagnosis, women across all the FGDs have a favorable attitude about prenatal diagnosis. Many viewed that testing for thalassemia during pregnancy should be made compulsory for couples who are both carriers.

Needs

Participants expressed concern about a wide range of needs related to feasibility and availability of screening and prenatal diagnostic facilities. They stressed that testing should be made more widely available, convenient, and most importantly, affordable to the general public. Many also wished for supportive health care systems that encourage and promote thalassemia screening. They viewed that knowing one's carrier status at an early age will have lesser psychological consequences.

Discussion

The focus group interactions have provided valuable insights into the knowledge, attitudes, and needs of general public in Malaysia. Although the Ministry of Health has in the past conducted thalassemia education campaigns through mass media, this study clearly indicates that it is essential to promote more awareness as only 68.6% of the participants have heard of thalassemia. It is a fact that unawareness causes people to overlook screening tests for diseases (Chattopadhyay 2006), and this should not happen with a disorder that has a carrier frequency of 4.5–6% in Malaysia.

The study also highlights some fundamental misconceptions which include erroneous beliefs that thalassemia minor exhibit signs and symptoms of thalassemia major, a child can inherit thalassemia major even if only one parent is a carrier, and perceived all thalassemia major are severely handicapped. Such misconceptions clearly lead to unnecessary anxieties and may have a profound effect among carriers. Public health messages should aim to demystify these misconceptions and encourage carrier testing that will eventually result in a reduction of thalassemia major births.

Across the focus groups, there was a better knowledge and fewer misconceptions in the younger, more educated participants. The Chinese appeared more broad-minded than the Malay and Indian groups. However, as the approach of this study was descriptive and qualitative in nature, the association between literacy level and knowledge/misconceptions and the ethnic disparities in perceptions to thalassemia cannot be evaluated. Interestingly, in a cross-country comparative study of knowledge of β-thalassemia, greater awareness and knowledge was not associated with education achievement but with intensive public awareness campaigns (Armeli et al. 2005). Public education and awareness campaigns in many countries have greatly reduced the frequency of infants born with thalassemia major (Angastiniotis et al. 1986; Gill and Modell 1988; Lakhani 1999). Thalassemia is a genetic disorder, and it will be a challenge to educate the low-educated and socioeconomically disadvantaged communities (Atkin et al. 1998). Responses from the FGDs indicated that an effective solution will be through multi-lingual leaflets with simple and clear illustrations on inheritance patterns. Other alternative strategies are to make available audio-visual information and personal experience sharing (Saxena and Phadke 2002; Ahmed et al. 2005).

This study highlights that prejudice and stigmatization is an obstacle to carrier screening for thalassemia in the Malay and Indian groups. This has also been encountered in other countries where carrier testing in extended family members received unfavorable responses due to fear of discrimination and adverse implications in marriage prospects

(Ahmed et al. 2002). Stigma and discrimination surrounding thalassemia rooted in misconceptions and erroneous beliefs. Chattopadhyay (2006) reported that awareness campaign will help to overcome misconception and stigma associated to thalassemia. A local study showed that mandatory school-based vaccination was perceived as able to increase awareness and reduce the stigma associated with receiving sexually transmitted disease vaccines (Wong 2009). Considering the social and psychological stress introduced by genetic diagnosis (Duster 1990), therefore, carrier screening for thalassemia at the school level together with accurate information may overcome stigma and misconceptions at an early age, as also reported by Gorakshakar and Colah 2009). In addition to the above, there are other psychological benefits of knowing one's carrier status at an early age, rather than finding out at a premarital test.

The findings of the FGDs with regards to attitudes toward termination of affected fetuses are in line with reported studies (Alkuraya and Kilani 2001; Garcia et al. 2008). Disapproval of abortion was based on moral and ethical implications. In spite of the unanimous disapproval due to ethical reasons, the participants' views about termination of pregnancy were closely influenced by their knowledge and perceptions about the survival rate, treatment and social consequences of thalassemia, and how all these issues will affect the entire family. No official data on the abortion rate due to thalassemia major in Malaysia has been collected as abortions are illegal in this country unless the mother's life is at risk. Reports in other countries have indicated that most affected couples will request termination of a pregnancy after diagnosis of major fetal abnormality (Modell et al. 1980; Ahmed et al. 2006b) and that the perception of disease severity is the main reason in a woman's decisions to terminate a pregnancy (Ahmed et al. 2006b).

In this study, the majority participants were unaware of the prevalence and the severity of β-thalassemia major. Of note, the subsequent change of the attitude of a minority of our study participants, who were unsupportive of termination of pregnancies, towards supportive of termination of fetus, after being informed that thalassemia major can live long lives if they have access to proper treatment, implies the importance of effective public education that will provide affected couples with the necessary information to allow them to make informed choices.

Numerous past studies showed that couples at risk of having a child with β-thalassemia major are in favor of termination of an affected pregnancy, in particular if prenatal diagnosis and termination of pregnancy are offered in the first trimester of pregnancy (Petrou et al. 1990; Modell et al. 1997; Ahmed et al. 2000; Ahmed et al. 2006b). Likewise, based on our findings, the participants also reported that the gestational age at the time of the offer of termination of pregnancy is important in deciding about an abortion. This indicates the importance of promotion of prenatal diagnosis in the earliest stage of pregnancy and provision of informed choices women need for considering abortion. In Malaysia, prenatal diagnosis for thalassemia is offered to the public at 200 Malaysian Ringgit as early as 12 weeks gestation using chorionic villi, and the results are known in 7 days. In the case where patient cannot afford to pay for prenatal diagnosis, the service is given free and the cost is absorbed by the University. Thus, a decision with regards to the pregnancy can be made in the 12th week of gestation, with is within the first trimester of pregnancy (Tan et al. 2004).

The Muslim community is committed to behave in compliance with their religious teachings and religious and local community leaders are closely involved in issues about prenatal diagnosis and termination of fetuses. However, it should be noted that religious teachings were not always the prime factor in a women's decision making about abortion issues (Ahmed et al. 2006b). The severity of thalassemia in the affected child, its social and familial impacts were also reported as the major factors in some Muslim couples' decision regarding prenatal diagnosis and termination of affected fetuses (Ahmed et al. 2006b). Our findings also support this as participants who were in contact with thalassemia major patients were more likely to support termination of affected pregnancies. It was surprising that some of the Muslim participants showed a change in attitude towards termination of pregnancy after the moderator explained the negative health and social outcomes of thalassemia major patients and their families. This important information should be kept in mind in public awareness campaigns for the Muslim community as it strongly indicates that knowledge allows informed choices that may be different from choices made by uninformed individuals.

Although thalassemia is a serious health problem and poses tremendous physical and psychological problems in the affected individuals, it is possible for thalassemia with major to enjoy a good life and to live a normal lifespan with proper coping strategies and supports. Coping with this disorder is a complex and dynamic process where individual patients and collective efforts of family, society, material resources, and health services (Atkin and Ahmad 2001). Public should be provided with all these information to enable them to make a voluntary and well-informed choice in screening practices and termination of pregnancies. Given this, a holistic approach to patient counseling, community education, and access to management of thalassemia services and support for clinical treatment is essential.

This study has identified thalassemia-related needs of Malaysians and has important implications in the development of health care service provision. The findings showed many participants expressed positive attitudes toward

thalassemia screening. Thus, promotion of screening is likely to receive a favorable response from the Malaysian general public. Hospitals and facilities with screening, premarital, prenatal, and genetic counseling facilities should be assessable, convenient, and readily available nationwide to promote testing. Specifically, the Muslim participants expressed needs in information about the religious aspects of prenatal diagnosis and termination of pregnancies. As such, information provision strategies in multi-religious society should meet the needs of participants where provision of information on the religious legal permission of abortion should be included. In particular, participants' desire for information about the prevalence thalassemia implies their interest to know the severity of thalassemia and assess their risk of getting the genetic disorder. This is in accord with health belief model (HBM), where action to prevent illness depends upon the individual's perception of susceptibility to acquire the disease, the severity of disease, and benefits of reducing the threat (Becker 1974). Future interventions should be carried out to test the HBM as a possible means of predicting public thalassemia screening practices in Malaysia. A HBM teaching program was reported to have significantly increased perceived susceptibility and severity and perceived benefits of blood screening practice (Lagampan et al. 2004).

Caution must be exercised when drawing conclusions beyond the sample assessed in the present study owing to the qualitative nature of the study. Thus, further investigation for generalization of findings using quantitative method is warranted. Secondly, all information obtained from the discussion was self-reported, thus self-report bias towards socially desirable responses might exist. Additionally, this study focused on attitudes rather than actual behaviors, and attitudes do not necessarily predispose one's actual behaviors (Ajzen and Fishbein 1980). Despite these methodological caveats, the sample comprised of participants from a diverse demographic backgrounds. The issues highlighted in this study are of considerable importance for the understanding of public's attitude towards thalassemia and have significant implications for promotion of effective campaigns in multi-ethnic societies. Most importantly, there have been few studies in a multi-racial population and this study provides data to fill the many gaps. There has been relatively scarce literature in Malaysia context and findings from the focus group discussions serve as valuable information and useful addition to the international body of literature.

Conclusion

In summary, the present results clearly document a strikingly low level of knowledge about thalassemia in this Malaysian sample and highlight the urgency of implementing effective public educational programs. The results of the present study also highlight the necessity of a holistic approach where public education and promotional activities should be accorded to local cultural and religious beliefs. These findings suggest that comprehensive and multi-sectoral approaches are needed to promote screening for thalassemia. These include increase publicity to stimulate concern and enhance perceived risk, enhance access to thalassemia screening, patient education, and school-based promotion and screening programs.

Acknowledgment The study is funded by University of Malaya (research grant FS326/2008C).

Competing interests The authors declare that they have no competing interests.

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