AWARENESS OF THALASSEMIA AND ATTITUDE TOWARDS THALASSEMIA SCREENING AMONG STUDENTS IN THE HEALTH CAMPUS, UNIVERSITI SAINS MALAYSIA

NUR AKILAH BINTI MOHD HILMI

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by

NUR AKILAH BINTI MOHD HILMI

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TABLE OF CONTENT

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATION

USM	Universiti Sains Malaysia
MOH	Malaysian Ministry of Health
MTR	Malaysian Thalassemia Registry
TDT	Transfusion-Dependent Thalassemia
HBM	Health Belief Model
MBBS	Bachelor of Medicine and Bachelor of Surgery
PPSK	School of Health Sciences
PPSP	School of Medical Sciences
PPSG	School of Dental Sciences

KESEDARAN TERHADAP TALASEMIA DAN SIKAP TERHADAP SARINGAN THALASEMIA DALAM KALANGAN PELAJAR DI KAMPUS KESIHATAN UNIVERSITI SAINS MALAYSIA

ABSTRAK

Talasemia adalah penyakit darah yang diwarisi yang mencetuskan morbiditi dan kematian. Ia disebarkan melalui corak resesif autosomal. Seperti yang diketahui, program saringan talasemia berkesan dalam mengawal prevalens kes kelahiran baru. Kajian ini bertujuan untuk menilai kesedaran talasemia dan sikap terhadap saringan talasemia dalam kalangan pelajar di Kampus Kesihatan, USM. Kajian keratan rentas telah dijalankan ke atas pelajar berumur 19 hingga 26 tahun. Data dikumpul menggunakan soal selidik yang ditadbir sendiri. Seramai 211 pelajar dari Pusat Pengajian Sains Kesihatan, Pusat Pengajian Sains Perubatan dan Pusat Pengajian Sains Pergigian, USM yang memenuhi kriteria inklusi telah terlibat dalam kajian ini. Mereka dipilih melalui kaedah persampelan rawak mudah kebarangkalian. Data yang dikumpul dianalisis secara statistik menggunakan perisian SPSS versi 27. Data kajian dianalisa menggunakan statistik deskriptif dan Pearson Chi-square. Hasil kajian menunjukkan 125 (59.2%) peserta mempunyai tahap kesedaran yang sederhana terhadap talasemia dan 88 (41.7%) peserta masing-masing mempunyai sikap positif terhadap saringan talasemia. Tidak terdapat perkaitan antara skor kesedaran dan skor sikap ($p = 0.093$), keputusan menunjukkan hanya 32 (47.1%) peserta yang mempunyai kesedaran yang baik dan sikap positif. Akhir sekali, tiada perkaitan antara faktor sosiodemografi [umur ($p = 0.119$), jantina ($p = 0.774$), etnik ($p = 0.228$), tahun pengajian ($p = 0.234$), sejarah keluarga talasemia ($p = 0.739$)] dan tahap kesedaran tentang talasemia. Kesimpulannya, tahap kesedaran tentang talasemia dan sikap terhadap saringan talasemia dalam kalangan pelajar perlu dipertingkatkan dan ditambah baik agar mereka lebih berpengetahuan untuk meningkatkan kesedaran tentang talasemia dan turut membantu menyebarkan program saringan talasemia kepada orang ramai.

AWARENESS OF THALASSEMIA AND ATTITUDE TOWARDS THALASSEMIA SCREENING AMONG STUDENTS IN THE HEALTH CAMPUS, UNIVERSITI SAINS MALAYSIA

ABSTRACT

Thalassemia is an inherited blood disorder that poses a significant cause of morbidity and mortality. It is transmitted as an autosomal recessive pattern. It is known that thalassemia screening programmes are effective in controlling the prevalence of new birth cases. The study aims to assess the awareness of thalassemia and attitude towards thalassemia screening among students in the Health Campus, USM. A cross-sectional study was conducted on students aged 19 to 26 years old. Data was collected using a self-administered questionnaire. 211 students from the School of Health Sciences, School of Medical Sciences and School of Dental Sciences, USM who fulfilled the inclusion criteria of this study. They were selected through a probability simple random sampling method. Data collected were statistically analysed using the SPSS software version 27. The study used descriptive statistics and Pearson Chi-square. The results show that 125 (59.2%) of participants have an average level of awareness of thalassemia and 88 (41.7%) of participants have a positive attitude towards thalassemia screening respectively. There was no association between awareness score and attitude score ($p = 0.093$), the result shows only 32 (47.1%) of participants have good awareness and positive attitude. Lastly, there was no association between sociodemographic factors [age ($p = 0.119$), gender ($p = 0.774$), ethnicity ($p = 0.228$), year of study ($p = 0.234$), family history of thalassemia ($p = 0.739$)] and the level of thalassemia awareness. In conclusion, the level of thalassemia awareness and attitude towards thalassemia screening among students must be enhanced and improved so that they are more knowledgeable about preventing thalassemia and can help promote the thalassemia screening programme to the public.

CHAPTER 1

INTRODUCTION

1.1 Background of the study

Thalassemia is a genetic ailment caused by a lack of or a reduction in the formation of globin chains (alpha or beta) of haemoglobin which affects the production of red blood cells (Miri-Moghaddam et al., 2014). This disorder is inherited, meaning it can be passed down from generation to generation. A thalassemia carrier couple has a 25% chance of having a child with a thalassemia major, a 25 % child that is healthy and a 50 % child that will be a carrier (Karimzaei et al., 2015). Next, it is estimated that between 4.5 and 6% of Malays and Chinese in Malaysia are carriers of the genetic abnormality that causes thalassemia and Sabah appears to be the highest incidence of thalassemia major (Wong et al., 2011). Depending on the kind and the clinical severity, thalassemia can present with a wide variety of signs and symptoms, some of which include anemia, frequent infections, a lack of appetite, congestive heart failure, bone deformities, failure to thrive, iron overload, and splenomegaly (Ebrahim et al., 2019).

Thalassemia is associated with significant morbidity and mortality. Thalassemia also significantly affects patients' general mental health and quality of life (Etemad et al., 2021). Patient with major thalassemia needs psychosocial support to help them cope with the physical demands of the disease and life-long treatment such as regular blood transfusion and chelation therapy. Out of 8681 patients registered in the Malaysian Thalassemia Registry (MTR) from 2007 to 2018, there are about 614 patients lost to follow-up treatment which may cause early death due to complications such as hepatitis C, hepatitis B, HIV,

cardiomyopathy secondary to iron accumulation, short stature, pubertal delay, and osteoporosis (Mohd Ibrahim et al., 2020). The major causes of death in thalassemia patients are cardiac failure and infections reported by the Malaysian Thalassemia Registry (2022) (Mohd Ibrahim et al., 2020). Therefore, awareness about thalassemia, its prevalence, severity, and treatments are crucial to preventing any major death cases.

Furthermore, besides blood transfusion therapy, bone marrow transplantation is a safe and effective treatment for thalassemia patients, especially if the donor is from siblings. However, it is a high-cost treatment and not everyone can afford that. Also, both treatments place a significant financial burden on the Malaysian health system. The Malaysian government pays for the therapy, including the chelation agent, and subcutaneous desferrioxamine (Mat et al., 2020). Therefore, it is important to strengthen the screening programme as the primary prevention of thalassemia to reduce the burdens on patients and the government.

For many years, thalassemia screening programmes have been implemented in several countries. Each country has it's own mandatory versus voluntary screening. Cyprus is one of the successful countries that reduced thalassemia prevalence by obliging premarital screening for hemoglobinopathies (Nor et al., 2022). In 2004, Thalassemia Prevention and Control Programme were established by the Malaysian Ministry of Health (MOH) to reduce morbidity and mortality among thalassemia patient, to prevent and control the prevalence of blood transfusion-dependent thalassemia cases and create awareness regarding thalassemia. After several years, MOH began offering prenatal screening and genetic counselling to at-risk couples attending public health clinics in 2008. Then, moving forward, MOH also encourages couples to do premarital thalassemia screening before marriage. In 2016, the school thalassemia screening programme for fourth-form students was established to detect beta thalassemia trait (carrier). These initiatives can prove the

decreasing trend of thalassemia prevalence and observe the public attitude to screen for the carrier status of thalassemia. Subsequently, we can assess their awareness regarding thalassemia disease.

1.2 Problem statement

For most diseases, prevention is better than cure; however, for most genetic diseases, including hemoglobinopathies (thalassemia), prevention is the only option. Screening thalassemia program has been found to be very effective in controlling the prevalence of new birth cases including screening for carriers in the community, genetic counselling, prenatal diagnosis, and premarital screening (Wong et al., 2003). Also, the Malaysian Ministry of Health (MOH) has organized a thalassemia screening for 15–16-year-old school students for the past few years. After many years of implementing the thalassemia screening programme, the number of affected births has decreased since 2015 (Mohd Ibrahim et al., 2019). However, a lack of knowledge and awareness of the disorder, its consequences, and psychosocial and cultural issues may prevent prevention, disclosure of disease status, and testing for thalassemia (Wong et al., 2011).

Additionally, a recent 2022 study found the level of thalassemia awareness among unmarried individuals in Kota Bharu was low, the same as in other Middle Eastern and Asian countries (Nor et al., 2022). Other than that, several worldwide studies revealed that attitudes toward prenatal diagnosis were related to religious beliefs (Wong et al., 2011). They are unwilling to abort the fetus with a potential thalassemia major gene because it is against religion for Muslims and it is God's fate, even though the pregnancy was less than 120 days, which fits with the Islamic ruling of abortion for babies with thalassemia major (Nor et al., 2022).

Furthermore, a study by Nor et al. (2022) stated that 62.2% of premarital course respondents knew that thalassemia is hereditary but there is no knowledge of the difference in the types of thalassemia and 87.1% of the respondent stated that they were unsure whether carriers of thalassemia would pass on major or minor thalassemia to their child. Moreover, there is also unclear information on the inheritance of thalassemia, they thought that a marriage between a normal person and a thalassemia minor could result in a thalassemia major child, a study conducted on medical students in Delhi (Pujani et al., 2017). Also, there is limited study regarding awareness and attitude toward thalassemia among university students in Malaysia. Hence, public understanding of thalassemia is vital in improving the government screening program because adequate knowledge and awareness positively correlate with individual attitudes toward genetic screening as the primary preventive measure against thalassemia (Noeriman et al., 2020).

1.3 Research Question

1) What is the level of thalassemia awareness among students in the Health Campus, USM?
2) What is the level of attitude towards thalassemia screening among students in the Health Campus, USM?
3) Is there any association between awareness of thalassemia and attitude towards thalassemia screening among students in the Health Campus, USM?
4) Is there any association between sociodemographic factors (age, gender, ethnic, year of study, family history) and the level of thalassemia awareness among students in the Health Campus, USM?

1.4 Research Objective

1.4.1 General Objective

To assess the level of thalassemia awareness and the level of attitude towards thalassemia screening among students in the Health Campus, USM.

1.4.2 Specific Objective

i) To determine the level of thalassemia awareness among students in the Health Campus, USM.

ii) To determine the level of attitude towards thalassemia screening among students in the Health Campus, USM.

iii) To determine the association between awareness of thalassemia and attitude towards thalassemia screening among students in the Health Campus, USM.

iv) To determine the association between sociodemographic factors (age, gender, ethnicity, year of study, family history) and the level of thalassemia awareness among students in the Health Campus, USM.

1.5 Hypothesis

Null Hypotheses (H_0): There is no significant association between awareness of thalassemia and attitude towards thalassemia screening among students in the Health Campus, USM.

There is no significant association between sociodemographic factors and the level of thalassemia awareness among students in the Health Campus, USM.

Alternative Hypotheses (H_1): There is a significant association between awareness of thalassemia and attitude towards thalassemia screening among students in the Health Campus, USM.

There is a significant association between sociodemographic factors and the level of thalassemia awareness among students in the Health Campus, USM.

1.6 Conceptual and Operational Definitions

Thalassemia	Thalassemia is an inherited blood disorder characterised by defective synthesis of one or more globin chains (Alpha or beta) in red blood cells and passed down from parent to children as an autosomal recessive trait (Etemad et al., 2021). In this study, thalassemia is being assessed according to Ghafoor et al.'s awareness level, 2020.
Awareness	Awareness is a state of being aware or conscious about something. It is the knowledge that a person has about in

	a situation or some condition (Meriam-Webster, n.d.). In this study, the level of awareness is being assessed among students in the health campus, USM in section b of the questionnaire. The higher the correct answer score, the higher the awareness level (Ghafoor et al., 2020).
Thalassemia screening	Thalassemia screening is a government initiative programme to control a new birth case of thalassemia and reduce morbidity and mortality of thalassemia patients. In this study, thalassemia screening refers to thalassemia screening programs, including screening for carriers in the community, genetic counselling, prenatal diagnosis, premarital screening, and school thalassemia screening for fourth-form students (Wong et al., 2003).
Attitude	"Attitudes are the persistent positive or negative appraisals, feelings, and behavioural tendencies of an individual toward objects or ideas."—David Krech, Richard S. Crutchfield, and Egerton L. Ballackey (iEduNote, 2022). In this study, an attitude refers to positive, neutral or negative feelings towards thalassemia screening which are measured in section c of the questionnaire (Pujani et al., 2017). The highest score of the correct answer will be taken as a positive attitude (Alzahrani et al., 2022).

1.7 Significance of the Study

The success of thalassemia prevention programmes in some countries has shown that using a retrospective screening method (prenatal, premarital, retrospective counselling) reduced cases by more than 90% (Buang et al., 2017). Besides, MOH's public awareness initiatives have given positive outcomes: the incidence of new thalassemia cases, the current overall trend of affected births and newly diagnosed Transfusion-Dependent Thalassemia (TDT) cases were decreasing from 2015 onwards (Mohd Ibrahim et al., 2020). Nevertheless, the study in Kota Bharu showed that knowledge about thalassemia remains low despite the MOH's extensive health education and promotion efforts (Nor et al., 2022). Some thalassemia screening attitudes and intentions are also wrong. Another study in the Udupi district, India, among young women showed that 36.8% of participants had poor awareness of thalassemia, and 70.7% of participants stated that premarital screening is not essential to rule out Thalassemia (Rishmitha et al., 2022).

Despite the recent move by the Malaysian Ministry of Health (MOH) to screen secondary students for thalassemia, it is still necessary to assess the level of thalassemia awareness and attitude towards thalassemia screening. Therefore, this study attempts to determine how much students in the health campus, USM are aware of thalassemia and its screening because adequate awareness aid in making life decisions such as screening for carrier status and deciding on consanguineous marriages.

The researcher believes that the higher awareness of thalassemia among young adults, aged 18 years and above can contribute to strengthening thalassemia screening in the future, especially for premarital screening. Lastly, the researcher also believes that raising public awareness will increase people's willingness to get tested for thalassemia and subsequently show a positive attitude towards thalassemia screening.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

This literature review discusses thalassemia, its prevalence, the types of thalassemia screening as thalassemia prevention, the level of thalassemia awareness and the level of attitude towards thalassemia screening in the community. This chapter also described the conceptual framework used in this study in detail.

2.2 Thalassemia

Thalassemia is an inherited blood disorder characterised by defective synthesis of one or more globin chains in red blood cells and passed down from parent to children as an autosomal recessive trait (Etemad et al., 2021). Reduced globin chain synthesis will affect the body's ability to produce haemoglobin, a protein found in red blood cells, eventually leading to varying degrees of microcytic anaemia (Nor et al., 2022). Haemoglobin is an essential protein in forming a healthy red blood cell, which transports oxygen from the lungs to the rest of the body's tissues, and it is made of two different parts, alpha and beta. Therefore, two types of thalassemia are classified depending on the nature of gene mutation: alpha thalassemia and beta thalassemia (Suriea et al., 2021).

This disease is transmitted as an autosomal recessive pattern. Parents pass on thalassemia traits to their children (Ghafoor et al., 2020). Suppose a married man and woman are a carrier of thalassemia, the possibility to have children with severe thalassemia is 25%. In that case, the children will be healthy is 25% and the children are carriers will be 50% (Karimzaei et al., 2015). Each year, approximately 240 million people worldwide

are heterozygous for beta-thalassemia (Thalassemia carriers), and approximately 200,000 homozygotes (transfusion-dependent Thalassemia) are born (Ghafoor et al., 2020).

According to the WHO report, thalassemia is present in more than 60 countries (Etemad et al., 2021) and estimated that approximately 1.67% of the global population are thalassemia gene carriers (Luo et al., 2022). Thalassemia is a global health concern due to its high prevalence and lack of a cure (Suriea et al., 2021). The prevalence of alpha-thalassemia is higher in communities from Asia and Africa. In contrast, the prevalence of beta-thalassemia is higher in populations from the Mediterranean region, even though it is also relatively common in Southeast Asia and Africa (Kattamis et al., 2020). In Malaysia, approximately 4.5% of Malaysians are beta-thalassemia carriers and the affected births per 1,000 are estimated to be 2.1 per 1,000, with an estimated 5,600 patients suffering from transfusion-dependent beta-thalassemia (Wong et al., 2011).

Furthermore, thalassemia can be classified into two categories: minor thalassemia and major thalassemia. Minor thalassemia is a person receives a thalassemia gene from one parent and a normal haemoglobin gene from the other. This person may have no symptoms or only mild anemia. In contrast, a person with thalassemia major may have severe symptoms and require frequent blood transfusions (Centres for Disease Control and Prevention, 2022). Major thalassemia is caused by inheriting the thalassemia gene from each parent especially if the parent is a beta-thalassemia carrier (Centre for Clinical Haematology, 2022). Major thalassemia is also called Transfusion-Dependent Thalassemia (TDT), they require regular blood transfusions to survive, and if they do not receive adequate transfusion support, they will suffer from various complications that will shorten their life (Rishmitha et al., 2022). The signs and symptoms of thalassemia depend on the type and clinical severity which include anemia, frequent infections, fatigue, a lack

of appetite, pale or yellowish skin, congestive heart failure, facial bone deformities, failure to thrive, iron overload, and splenomegaly (Ebrahim et al., 2019; Mayo Clinic, 2021).

The treatments are also depending on the type and severity of the thalassemia. Mild thalassemia usually does not need any treatment especially for asymptomatic. However, they will occasionally need a blood transfusion after surgery or giving birth if necessary (Bajwa & Basit, 2022). For moderate to severe thalassemia with a haemoglobin level of less than 5 to 6g/dl, the treatments are blood transfusion, chelation therapy and hematopoietic stem cell transplantation also called bone marrow transplant. Regular blood transfusion remains the main standard treatment for thalassemia major. Approximately 2400 transfusion-dependent Thalassemia patients in Malaysia are estimated to receive regularly packed cell transfusions 3-4 times per week to alleviate the disease's chronic anemia (Chiruka & Darbyshire, 2011).

Nevertheless, the exact number is unknown due to the current lack of a patient registry. Next, chelation therapy is needed to remove extra iron from the body due to chronic blood transfusion. The standard chelation therapy drug is Desferrioxamine (DFO) which is mostly administered by subcutaneous infusion in a high dose for five days per week (Chiruka & Darbyshire, 2011). Another iron chelator monotherapy prescribed was deferasirox (DFX) and deferiprone (DFP)(Mohd Ibrahim et al., 2020). Last but not least, a bone marrow transplant is one of the effective and safe treatments, especially if the donor is from siblings however, there are also risks, such as graft failure and transplantation-related mortality (Jariwala et al., 2019). Also, it is a high-cost treatment and thus unaffordable for many people in developing countries.

2.3 Thalassemia Screening

Patient with thalassemia major needs a life-long treatment such as blood transfusion and chelation therapy which may have serious complications. The treatments give such a burden in terms of physical health, including physical changes, delay in growth, and sexual maturity, financial due to treatment costs and barriers in learning for higher education due to the time demand for treatment needed (Etemad et al., 2021). Moreover, the treatment option imposes a significant financial burden on Malaysia's healthcare system because the government pays for the therapy, including the chelation agent, and subcutaneous desferrioxamine (Mat et al., 2020). As a result, prevention is the only way out of this socioeconomic burden.

Primary prevention for thalassemia is through screening programmes for the high-risk community. Population screening for carriers is the most effective way to reduce its occurrence and is used in many countries (Murthy et al., 2017). The goals of beginning the prevention programme are to lessen the new birth of blood transfusion-dependent thalassemia, lower the cost of implications in providing optimal care for patients, and reduce the life-long socioeconomic burden on patients, families, and the government (National Thalassemia Screening Program, 2016). The Malaysian Ministry of Health (MOH) was organized thalassemia screening programmes for the past few years as below. Premarital screening and prenatal diagnosis help reduce thalassemia's prevalence and future incidence (Ahmed et al., 2018).

2.3.1 Prenatal Diagnosis

In 2008, the Malaysian Ministry of Health (MOH) started offering prenatal diagnosis, and genetic counselling to at-risk couples attending public health clinics. The couples must receive qualified counselling before undergoing prenatal diagnosis. They must clearly understand the level of genetic testing or diagnosis that has been offered,

thalassemia-screening results and the risk to the offspring to provide informed consent (Li & Yang, 2017). Furthermore, invasive prenatal diagnosis can be performed from the first trimester by chorionic villus sampling (CVS) to the second trimester by amniocentesis or cordocentesis. Chorionic villi, amniotic fluid, or fetal blood cells can be used for DNA analysis (Li & Yang, 2017). Before invasive procedures, blood samples from both parents are required to confirm the carrier status of a thalassemia mutation and to serve as a source of control DNA for prenatal molecular analysis.

Next, suppose the result of prenatal diagnosis obtained that the fetus had a major thalassemia trait before 120 days of fetal life. In that case, they are advised to abort the fetal if it is causing harm to the mother or fetus or both and if the couples agree. Considering Islam is the major religion in Malaysia, abortion is prohibited. However, based on The Penal Code (Amendment) Act 1989 (Act A727), therapeutic abortion is permitted which allows abortion within 120 days of conception if it poses a greater threat to the mother's life or physical or mental health than the termination of the pregnancy (Mohd Ibrahim et al., 2020). Moreover, according to the 52nd Muzakarah Jawatankuasa Fatwa Majlis Kebangsaan Bagi Hal Ehwal Ugama Islam Malaysia, it is 'makruh' (a disliked act) if abortion is performed between 1 and 40 days of fetal life, if it does not harm the mother, and it is 'harus' (a recommended act) if abortion is performed before 120 days of fetal life if the fetus is disabled or causes harm to the mother. Lastly, it is 'haram' (a forbidden act) if abortion is performed after 120 days of fetal life because the 'roh' (soul) of the fetus has been incorporated at this point based on the Islamic point of view, unless the pregnancy will be causing harm to the mother (Nor et al., 2022).

2.3.2 Premarital Screening

In Malaysia, premarital health screening is required when the couple decides to get married. A premarital health screening includes a combination of standard health screenings and more specialised tests for inherited abnormalities, fertility, and sexually transmitted diseases (STDs). These tests are necessary because most couples may be unaware of any health issues or genetic abnormalities they have, especially if there are no symptoms (Batrisya, 2022). The screening is intended to take early precautions for potential health problems such as infectious disease, hereditary blood disorders or any sexual history that could endanger the partner or future offspring. The most common test package for premarital screening includes full blood count, peripheral blood film and blood grouping, Venereal Disease Research Laboratory (VDRL), Hepatitis B Screening and HIV.

Nevertheless, hemoglobinopathies test to detect the thalassemia trait gene also is common however it does not make mandatory to do this test because Malaysia currently has no policy on thalassaemia-carrier screening for couples before marriage (Albashri et al., 2018). Only premarital HIV testing is mandatory for prospective Muslim married couples (Barmania & Aljunid, 2017).

2.3.3 School Thalassemia Screening

In 2016, MOH introduced thalassemia screening among Form 4 students and 31,716 carriers were detected out of 689,460 screened students (The Malaysian Reserve, 2021). The school settings of thalassemia screening have the advantage of reaching the majority of the population. It is much easier to provide health education to those identified as carriers such as giving an option not to marry another carrier (National Thalassemia Screening Program, 2016). Screening of school students above 16 years old has been successful in many countries without incurring any psychological and social harm (National Thalassemia Screening Program, 2016). Moreover, screening among teenagers

is effective as they are still young and unmarried (The Malaysian Reserve, 2021). Besides that, the government chose the age range of 15 to 16-year-old to do the screening because their blood has the same parameter readings as an adult, making it easier to interpret and classify (The Malaysian Reserve, 2021). The screening procedures involved are taking a family history and blood sample for full blood count, haemoglobin analysis and iron studies (Jameelah et al., 2011).

2.4 Awareness of Thalassemia and its associated factors

Many countries, including Iran, Greece, Italy, and Cyprus, have successfully controlled thalassemia by launching education campaigns, and awareness programmes, and emphasising preventive measures. Thus, it is critical to raise public awareness of these challenges (Ghafoor et al., 2020). After many years of implementing the thalassemia screening program, there is a declining trend of affected births from 2015 onwards. From 2014 to 2018, new thalassaemia births decreased steadily, particularly in Sabah, which could be attributed to increased public awareness because of government initiatives and secondary school screening (Mohd Ibrahim et al., 2019). Nevertheless, many studies showed the level of awareness towards thalassemia is still poor in the community. One of the studies showed the level of awareness among non-medical individuals is poor compared to medical individuals in terms of awareness of diagnosis from blood, management, premarital screening, and various treatment modalities (Blood Transfusion, Bone Marrow Transplant), fatality and severity of the disease (Ahmed et al., 2018).

However, in some cases, medical professionals also had deficient awareness regarding prenatal diagnosis and chorionic villous sampling. Next, most participants in Malaysia are unaware of the prevalence of thalassemia in the country, as nearly half believe it is a very rare, non-serious, or uncommon disease. They believed that a lack of

information was the primary cause of thalassemia awareness among the public (Murthy et al., 2017). A lack of knowledge and awareness of the disorder, its consequences, and psychosocial and cultural issues may prevent prevention, disclosure of disease status, and testing for thalassemia (Wong et al., 2011).

Next, a recent study involving rural Penang participants showed factors associated with thalassemia awareness are the younger age group and a higher level of education (Nor et al., 2022). Then, another study showed the participants with a positive family history or who had previously been tested for beta-Thalassemia had significantly more knowledge of thalassemia (Ghafoor et al., 2020). Moreover, in a high school study in Iran, students' awareness increases with age due to their ability to use books, media, and social communication. Hence, students' educational level significantly increases knowledge about disease nature and prevention (Miri-Moghaddam et al., 2014). Lastly, thalassemia awareness was higher in the high-income, high-education, and professional and managerial categories (Wong et al., 2011).

2.5 Attitude towards Thalassemia Screening

The community's attitude towards thalassemia screening seems positive as they agreed that thalassemia screenings are necessary for the public. In one study at Kota Bharu, the percentage of premarital screening are high like in a previous study in Middle Eastern countries such as Oman, Turkey, and Saudi Arabia, with approximately 31.7% of the respondents agreeing that two thalassemia carriers who were a couple should not get married (Nor et al., 2022). Next, a study among Indian medical students on thalassemia showed that approximately 90.2% of the MBBS students were willing to participate in community awareness and prevention programs (Pujani et al., 2017). They also suggest that premarital screening should be made mandatory for the public.

Furthermore, several studies worldwide found that attitudes toward prenatal diagnosis were related to religious beliefs. Especially for Muslim couples have been reported to refuse prenatal diagnosis on religious grounds (Wong et al., 2011). They were unwilling to abort the fetus with a potential thalassemia major gene because it is against religion for Muslims and it is God's fate, even though the pregnancy was less than 120 days, which fits with the Islamic ruling of abortion for babies with thalassemia major (Nor et al., 2022). Thus, early carrier screening, like secondary school and premarital screening is better than a prenatal diagnosis (Ebrahim et al., 2019). Lastly, various parameters like age, gender, region, and socio-economic class did not affect the attitude (Pujani et al., 2017).

2.6 Theoretical/Conceptual Framework of the Study

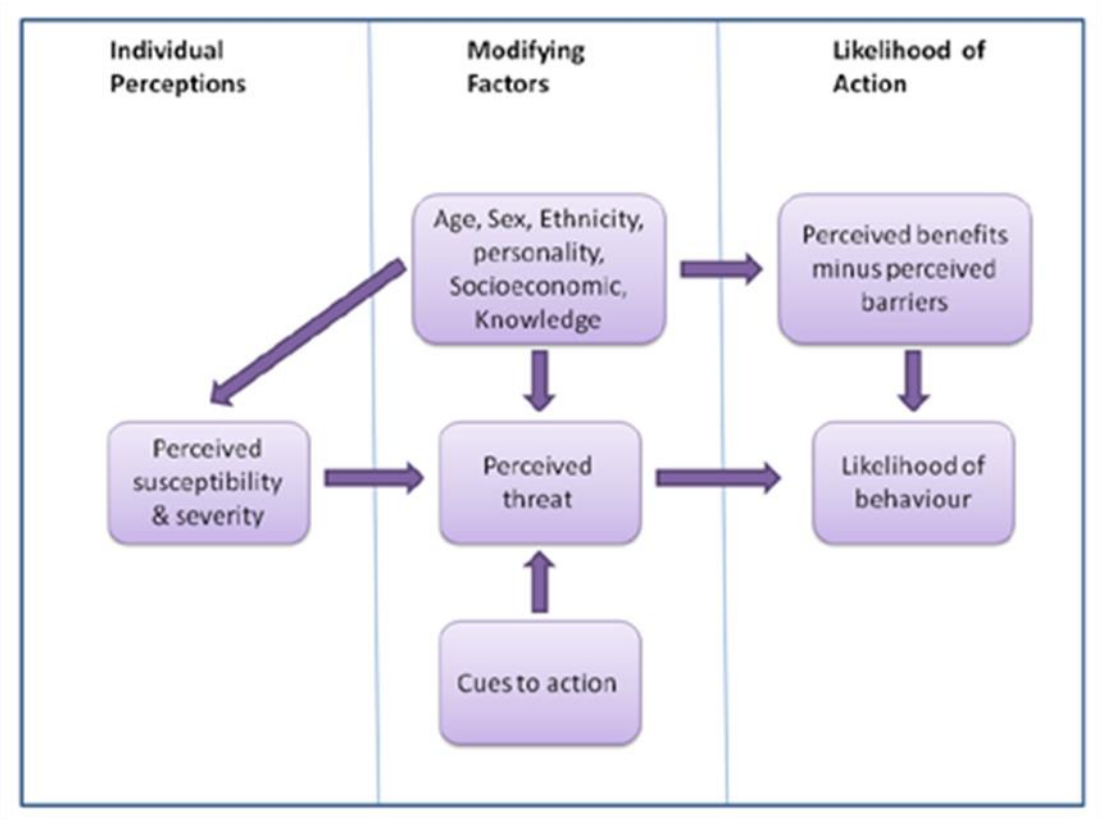

Figure 2.1 The Health Belief Model adopted from Glanz, Rimer & Lewis (2002)

The researcher used the Health Belief Model (HBM) to understand health-promoting behaviours. This model has been selected as the theoretical framework for this study. HBM was designed in the 1950s by social psychologists. According to HBM, every person's behaviour is influenced by their perceptions of various aspects of behaviour, and changing these perceptions can lead to behavioural changes (Karimzaei et al., 2015). The HBM is made up of 6 key constructs: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy.

For this study, the researcher wants to determine the level of thalassemia awareness and attitude towards thalassemia screening among students in the health campus, USM. HBM explain that the level of thalassemia awareness can be influenced by several modifying factors such as sociodemographic factors. It also can affect an individual's perceptions towards thalassemia screening. The change of these perceptions can lead to behavioural changes such as participating in the thalassemia preventive programme. These perceptions also are influenced by several modifying factors such as demographic data. Besides that, HBM training intervention effectively changes attitudes and practices. The desire for information about thalassemia prevalence indicates the participant's desire to understand the severity of thalassemia and assess their risk of contracting the genetic disorder. This is consistent with the HBM, which states that any action taken to prevent illness depends on on the individual's perception of susceptibility to disease and awareness of the benefits of reducing the threat of disease (Kia et al., 2018).

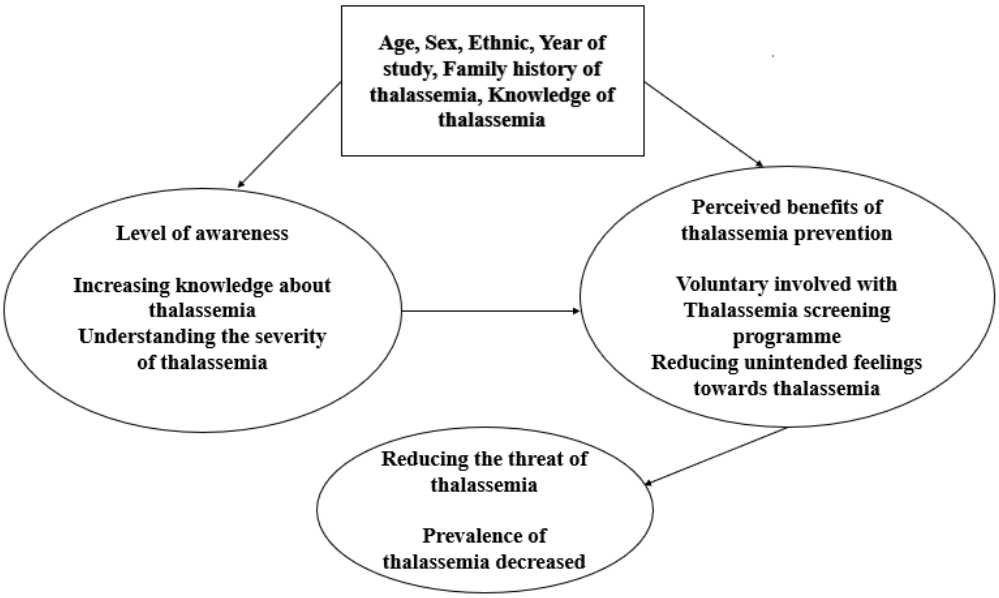

Figure 2.2 Conceptual framework of the study for awareness of thalassemia and attitude towards thalassemia screening.

CHAPTER 3

METHODOLOGY AND METHOD

3.1 Research Design

The research design selected for this study was a cross-sectional study. The participants were selected based on the inclusion and exclusion criteria set for the study. The selected participants were following the study to assess their level of awareness of thalassemia and the level of attitude towards thalassemia screening as well as the association of selected sociodemographic characteristics with the participants' awareness of thalassemia. The advantages of cross-sectional study include do not require a lot of time, being inexpensive, and can be carried out at a one-time point or over a short period (Setia, 2016).

3.2 Research Location

This study was conducted in Health Campus, Universiti Sains Malaysia, Kubang Kerian, Kelantan.

3.3 Research Duration

This study was conducted from October 2022 until August 2023.

3.4 Research Population

This study was conducted among students at Health Campus, Universiti Sains Malaysia. This campus has three main schools: the School of Medical Sciences, School of Dental Sciences and School of Health Sciences with a total of 14 academic programmes. Table 3.1 shows the list of programmes in each school.

Table 3.1 List of programmes in each school

School	Programme
School of Medical Sciences	Medical
School of Dental Sciences	Dental
School of Health Sciences	Audiology Biomedicine Dietetics Environmental and Occupational Health Exercise and Sport Science Forensic Science Medical Radiation Bachelor in Nursing Diploma in Nursing Advanced Diploma in Renal Nursing Nutrition Speech and Pathology

3.5 Subject Criteria

Inclusion Criteria	Exclusion Criteria
Undergraduate students	Students who have been diagnosed with thalassemia minor or major, or thalassemia carrier
Age 18 years old and above	

3.6 Sampling Plan

3.6.1 Sample Size Estimation

The sample size was calculated for each study objective. The researcher has chosen a relatively greater number of participants at the end to fulfil the research objectives.

The sample size was estimated using a single proportion formula. For the first objective (to determine the level of thalassemia awareness among students in the Health Campus, USM)

$$n = \left(\frac{z}{\Delta}\right)^2 p(1-p)$$

whereby,

n = required sample size

z = value representing the desired confidence level, $z_{0.05} = 1.96$

Δ = desired level of precision, ± 5%

p = anticipated population proportion = level of awareness = 0.26 (Ghafoor et al., 2020)

Calculation:

$$n = \left(\frac{z}{\Delta}\right)^2 p(1-p)$$

$$n = \left(\frac{1.96}{0.05}\right)^2 0.26(1-0.26)$$

$$n = 295$$

The minimal sample size is estimated at 295, and after considering a 10% dropout due to the involvement of a wide population in each cluster, the sample size calculated is

$$n = 295 + 10\%$$
$$n = 295 + 30$$
$$n = 325$$
$$n = 325\ participants$$

Therefore, the sample size needed for the first objective in this study is 325 participants who fulfilled the inclusion and exclusion criteria.

Meanwhile for the second objective (to determine the level of attitude towards thalassemia screening among students in the Health Campus, USM),

$$n = \left(\frac{z}{\Delta}\right)^2 p(1-p)$$

whereby,

n = required sample size

z = value representing the desired confidence level, $z_{0.05} = 1.96$

Δ = desired level of precision, ± 5%

p = anticipated population proportion = level of attitude towards thalassemia screening = 0.88 (Nor et al., 2022).

Calculation:

$$n = \left(\frac{z}{\Delta}\right)^2 p(1-p)$$

$$n = \left(\frac{1.96}{0.05}\right)^2 0.88(1-0.88)$$

n =162

The minimal sample size is estimated at 162, and after considering a 10% dropout, the sample size calculated is

$n = 162 + 10\%$

$n = 162 + 16$

$n = 178$

$n = 178\ participants$

Therefore, the sample size needed for the second objective in this study is 178 participants who fulfilled the inclusion and exclusion criteria.