

Perceptions of thalassemia and its treatment among Malaysian thalassemia patients: A qualitative study

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RESEARCH

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ABSTRACT

Background

Thalassemia is a common public health problem in Malaysia and one of the most common chronic and genetic disorders.

Aims

The present qualitative study explores knowledge about thalassemia, perceptions about conventional therapies and the points that affect Malaysian patients with thalassemia in taking medications correctly.

Methods

This study used a qualitative method. Purposive and theoretical samplings were combined to explore the issues related to thalassaemia and its perceptions. Twenty-one patients with thalassemia were recruited from the Thalassemia Society, Kedah, Malaysia from July to October 2015. The semi-structured interviews were audio taped, transcribed verbatim and translated into English for thematic content analysis.

Results

Participants perceived thalassemia as an incurable disease which is due to genetic and blood related disorders. A positive perception was shown towards conventional therapies considering it as effective for their condition. High treatment cost was given as a reason why patients perceived conventional therapies as effective. Fear of side effects was the main reason the patients gave for their delay in looking for treatment. However, due to limited treatment options, patients were reported to show positive attitude towards the side effects due to thalassemia treatment.

Conclusion

This explanatory investigation suggests that thalassemia patients' understanding about thalassemia is complex in nature. The findings may help healthcare providers remove myths about the fear of the treatment. It may also help in improving patient's compliance towards the thalassemia therapies. Main focus for future research should be on those patients who declined the conventional therapies.

Key Words

Thalassemia, Malaysia, perceptions, qualitative

What this study adds:

1. What is known about this subject?

Thalassemia is the most commonly inherited single gene disorder.

2. What new information is offered in this study?

Information on thalassemia patients' beliefs and experiences regarding thalassaemia and their treatments is discussed.

3. What are the implications for research, policy, or practice?

The findings provide baseline information about patients' knowledge and perceived effectiveness of modern treatment which can help to design more specific educational program.

Background

The thalassemia disease is one of the most common genetic blood disorders. It is the most commonly inherited single gene disorder in the world. Thalassemia is a heterogeneous group of genetic disorders resulting in the reduced rate of production of one or more of the globin chains of haemoglobin while 200,000 affected homozygotes are born annually.^{1,2} They are widely distributed worldwide and it is estimated that there are 266 million thalassemia carriers with three hundred thousand children suffering from thalassemia around the world. It is more prevalent in certain areas especially among Asians as well as in the middle Mediterranean, Middle Eastern and Far Eastern populations. In Malaysia, 6,623 patients have been registered with the Malaysian Thalassemia Registry 2009. From this total number of registered patients, 4,463 (67 per cent) of them have been undergoing regular blood transfusion and iron chelation treatment.³ Every year, 200 cases are added to the registry. It is anticipated that the probability for every new patient to survive would be up to 30 years. With the statistics of one carrier in every 20 Malaysians, the Ministry of Health initiated a screening program in 2008 which aimed to reduce the birth of babies with thalassemia.⁴

Most of the children who are affected live in countries where resources are limited. Because of that, emphasis is placed more on handling higher rates of infant and child mortality rather than infections and malnutrition.⁵ As a result, hereditary disorders have received little attention and affected children may not receive the treatment they need. Eventually, these children end up dying during their childhood. Thalassemia is considered a lifelong illness requiring biomedical treatment shortly after birth and continues until death. Patients with thalassemia usually suffer early and late complications secondary to their disease. Early complications usually occur in relation to blood transfusions while late complications occur due to iron overload and underlying poorly treated disease. The current study aims to explore the thalassemia patients' experiences and knowledge about thalassemia and to explore perceptions towards conventional thalassemia therapies.

Methods

Design and settings

The study was approved by joint ethical committees of the School of Pharmaceutical Sciences, USM and Lam Wah Ee Hospital on Clinical Studies in Malaysia [reference: USM-HLWE/IEC/2015 (002)]. The study was conducted from July until October in 2015 at Kedah Thalassemia Society Centre in Alor Star in the state of Kedah, in the northern region of Peninsular Malaysia. According to Malaysian Thalassemia Registry 2014, the northern region had the highest number of thalassemia patients in the country.

Participants

For this study, purposive and theoretical samplings were combined to explore the issues related to the perception of thalassaemia and its treatment used among thalassemia patients.⁶ Patients were purposively selected from three major ethnic groups in Malaysia, namely Malay, Chinese and Indians. Recruitment was made until we reached theoretical saturation i.e. no new information emerged after the subsequent interviews thus fulfilling the requirement of theoretical sampling.⁷ The participants were selected among patients 18 years of age or older who were diagnosed with thalassemia disease. The recruitment was continued over a period of four months. Informed consent was obtained from each respondent by giving patients an information sheet in Malay and English to be read prior to the interviews. Patients who were unable to read and understand these two languages were given verbal information. The interview sessions were carried on until saturation point was met, that is when there was no new information acquired from later interviews. During the four-month period of data collection, almost 50 patients were asked whether they would like to participate in the study. A total of 21 patients agreed and were interviewed. The reasons given for those who did not participate were because of their medical condition and they were not available on the interview days.

Study tool

The interview sessions were carried out using interview guide which was formed after extensive literature review. Participants were asked about what they know of thalassemia, what kind of treatment they seek, and the options they have for thalassemia treatment. The questions given during the interview sessions were kept open-ended as much as possible in order to give the participants the greatest possible chance to give their views. Initially, four interview sessions were conducted in Jun 2015 as a pilot study in order to detect any problems or challenges associated to the interview to ensure that the study could

be conducted appropriately and also to modify interview guide if necessary.⁸

Data collection and data analysis procedures

Each semi-structured in-depth interview session lasted approximately for 45 to 60 minutes. Interviews were conducted in the Malay language. One-to-one interviews were conducted, thus having one patient per session. A total of 21 interviews were conducted. We reached saturation at 19th interview; however, two extra interviews were conducted to confirm the findings. The interviews sessions were recorded digitally and transcribed in English by the principal investigator. To ensure privacy, the identity of participants was kept confidential by using an identified unique number (P01 to P21). The principal investigator was present during the entire interview sessions.

The interview sessions were transcribed verbatim. The transcripts were reviewed and sent to the participants for approval. The transcripts were subjected to thematic content analysis including coding and identification of common or recurrent themes using comparative analytic process to identify emerging categories. This was done by the principal investigator and the co-researchers who were informed about the aims and objectives of this study. The data was further analyzed to assess the behaviour of each participant based on the unique codes.^{9,10} The principal investigator and the participants in the study shared a similar cultural background, spoke Malay and English in the Kedahan dialect. Hence, the principal investigator did not experience any communication barrier.

Results

Twenty-one patients (P01-P21) between the ages of 18 and 58 (Mean = 29 years) were interviewed. Because the Malays constitute the main ethnic group in Malaysia, they made up the highest (n=17) number of patients in the sample groups, followed by the Chinese (n=4). Most of the participants were from low-income group getting treatment in government hospitals. All of the patients, who were β thalassemia major and intermediate thalassemia, had no health insurance, and they had no other choice than to go to government hospitals for treatment. The demographic data are summarized in Table 1. During the analysis, three categories were identified beliefs regarding the causes of thalassemia, beliefs in the benefits of modern treatment, and experiences related to the side effects of modern treatment. Conventional or modern treatment for this study was those widely used in the modern health care system. The conventional treatment offered by hospital includes blood transfusion, surgery and chelation therapy.

Traditional ways of healing includes any treatment other than what has been offered by the hospitals.

Beliefs regarding the causes of thalassemia

When asked about thalassemia and why they had thalassemia, the participants gave different reasons according to the following subthemes: blood disease, genetic disorder, and spiritual coping mechanism.

Table 1: Demographic and disease characteristic of participants

Characteristic	N=21	%
<i>Age (Mean= 29)</i>		
18-30	13	62
31-40	7	33
41-50	0	0
51-60	1	5
<i>Gender</i>		
Male	6	29
Female	15	71
<i>Race</i>		
Malay	17	81
Chinese	4	19
<i>Religion</i>		
Islam	17	81
Buddhism	4	19
<i>Educational Status</i>		
Primary	2	10
Secondary	12	57
Diploma /Matriculation	7	33
<i>Socioeconomic Status *</i>		
Low (less than RM1000/month)	13	62
Middle (RM 1000–3000/month)	8	38
High (> RM 3000/month)	0	0
<i>Medical Insurance</i>		
Yes	2	10
No	19	90
<i>Marital Status</i>		
Single	13	62
Married	7	33
Divorce	1	5
<i>Type of Thalassemia</i>		
β -Thalassemia Major	13	62
IntermediateThalassemia	6	29
Thalassemia Minor (Trait)	2	10

[*Sources: Department of Statistic Malaysia, Official Portal 2015]

Blood disease

In this exploratory investigation, patients described thalassemia as only related to blood and could not be cured. "I do not know anything about thalassemia. I only know that

it is something that is related to blood". [P10, 23 years, female, Malay, β -thalassemia major]

"I only know that every month, I need blood or else I will be sick". [P19, 19 years, male, Chinese, β -thalassemia major]

Thalassemia patients reported themselves as dependent on blood transfusion.

"It is a blood disease. The blood needs to increase every month". [P5, 22 years, female, Malay, Intermediate thalassemia]

"Thalassemia is a disease where the red blood cell will burst in less than a month causing the person to be tired". [P9, 19 years, female, Malay, Intermediate thalassemia]

It was observed that patients understood thalassemia as a disease inherited from parents with thalassemia genes. It was found that blood transfusion is the most important treatment to those with thalassemia, especially β -thalassemia major and intermediate thalassemia patients, as this treatment would provide blood with normal haemoglobin to the patients in order to maintain the amount of red blood cells in the body.

Genetic disorder

Patients who have a history of thalassemia running in the family had a strong belief that thalassemia is a genetic disease.

"It is a genetic disease and I got it from my parents". [P5, 22 years, female, Malay, Intermediate thalassemia]

"I only know that it is an inherited disease because I got it from my parents, both of whom are carriers". [P12, 32 years, Female, Malay β -thalassemia major]

"I am a β -thalassemia major patient. I know that it is an inherited disease and it is related to blood. But my parents are not carriers. May be it came from my grandpa". [P16, 26 years, Female, Malay, β -thalassemia major]

Those who considered thalassemia as a genetic disorder showed their concerns towards the importance of screening. Patients perceived that early screening can benefit them. By knowing the severity of the disease, they can take appropriate actions.

"Now, my child is a β -thalassemia major. I often bring him to the hospital for treatments. Everybody loves their children

including my parents. But, they are no more. They always care for me when they were alive. I don't know I am a carrier until and I feel that my thalassemia is not as serious as my child". (P18, 57 years, Chinese, carrier)

Spiritual coping mechanism

Spiritual connection was found among all of the thalassemia patients. They were able to deal with it by having strong faith in their own respective religions.

"Thalassemia disease makes me closer to Allah Subhanahu wa Ta'ala (SWT). To remain calm and maintain my composure, I have sought solace and become closer spiritually with Allah and prayed Dhuha prayer". [P7, 29 years, Female, Malay, β -thalassemia major]

"I also do a lot of extra prayers, reciting the Qur'an and 'dzikr'. I feel that these bring me closer to Allah S.W.T.". [P10, 23 years, Female, Malay, β -thalassemia major]

"We need to accept the destiny and if it is God's will, then it will happen". [P21, 38 years Female, Chinese, carrier]

Most of the patients were Muslims and they felt that their sickness brought them closer to Allah S.W.T. It was found that most of the patients had the tendency to engage in more on spiritual development practices such as praying rather than merely physical exercises such as aerobics and going to spa as coping strategies for their ailments.

Beliefs in the benefits of modern treatment

Positive views regarding modern treatment

Backed by evidence from research

Participants had different perceptions regarding the effectiveness of conventional therapies. Thalassemia patients were satisfied with the current quality of the treatment of thalassemia compared to that of the previous years. They believed their thalassemia symptoms could be reduced by undergoing the therapies. Advanced new technologies for thalassemia treatment were the reasons given by the patients.

"I think that modern treatment is good and effective for my sickness". [P1, 38 years, female, Malay, Intermediate thalassemia]

"I believe that modern treatment is effective and I have been receiving treatment ever since I was a kid. If not, I would not have been able to do any work. I will depend on blood

transfusion, folic acid, dysferal and exjade". [P4, 24 years, female, Malay, β -thalassemia major]

"I believe in the effectiveness of the modern treatment because it works faster and is more effective even though those suffering from thalassemia cannot be cured. Modern treatment comes with evidence from research compared to the lack of evidence from the traditional ones. Today, the current conventional treatment is more effective compared to that of the previous years". [P10, 23 years, female, Malay, β -thalassemia major]

Modern treatment

Modern treatment for thalassemia is provided by hospitals. The patients perceived modern therapies as effective. Thalassemia patients would need to follow all the regulations given by the hospital, such as the schedule of blood transfusion and the medicines needed to be taken, in order to make sure the symptoms would be reduced. They perceived this as deficient in the traditional ways of healing.

Patients believed that the treatment they received was very effective especially in increasing their hemoglobin level in their blood compared to the traditional way which would be very time-consuming. For example, the iron chelation therapy treatment, that would eliminate iron after blood transfusion, would be way better than the traditional way which would have no specific ways of eliminating iron in the body.

"To me, the hospital's treatment works. I know that each treatment undergone is important but I do not know what the outcome of this continuous process is". [P5, 22 years, female, Malay, β -thalassemia major]

"I feel that taking medicines is effective. If I do not take the prescribed medicines, I am unable to work especially after having the blood transfusion". [P6, 36 years, female, Malay, Intermediate thalassemia]

Treatment Cost

One of the reasons why patients thought modern treatment is effective was because of its cost which is expensive.

"I believe in the effectiveness of the modern treatment because it works faster and is very expensive. Before this, we had to buy our own filter bag, unlike these days. It is more effective even though those suffering from thalassemia cannot be cured". [P10, 23 years, female, Malay, β -thalassemia major]

Negative views regarding modern treatment

The patients were constantly concerned about the adverse effects and they were also worried if the treatment would turn out to be a failure. Therefore, there were patients who felt that it was not worthwhile taking the conventional treatment.

"Antibiotics don't work. I am still sick.... I had to be warded for 5 months, unconscious due to brain infection or brain abscess. Doctor said that it was because of the blood transfusion done on me". [P1, 38 years, female, Malay, Intermediate thalassemia]

"For the blood transfusion, I am a bit worried whenever I think of the possible risks of getting infected with HIV and many more. But, gradually, I have got used to it. Now, whenever it crosses my mind, I quickly pray and hope for the best". [P12, 32 years, female, Malay, β -thalassemia major]

"Each time I take my dysferal, I feel weak and I am unable to do much work. We are always in pain from the needles but if we don't take it, we are dead." [P2, 26 years, male, Malay, β -thalassemia major]

"Taking dysferal caused me to be down with fever and L1 (deferiprone) caused me nausea and vomiting". [P7, 29 years, female, Malay, Intermediate thalassemia]

All of the participants were patients who had been receiving treatment from the hospital and they might have their own perceptions about the treatment they had undergone there, the effectiveness of the medicines and the modern treatment they had tried. However, there were some of them who compared traditional treatment with modern treatment they had undergone which did not give the outcomes they had hoped for. As a result, they did not follow the treatment nor take the medicines given by the hospital causing harm to their heart, liver and other organ failures due to inability to eliminate excessive iron in the body.

Experiences related to the side effects of modern treatment

Fear of blood transfusion

Most participants were worried about the side effects from blood transfusion and iron chelation therapy. Other major worries included the chances of them getting infections from viruses and bacteria. The participants were also frightened from serious co-morbidities such as cardiomyopathy. A strong disapproving view was noticed

among thalassemia patients where there was an increased level of anxiety each time after blood transfusion.

“My liver often swells maybe due to the frequent blood transfusion each month. My spleen often swells too. Sometimes I wonder if I keep on doing blood transfusion, am I going to be infected with Hepatitis C virus for example, because many of those with thalassemia got hepatitis C”. [P5, 22 years, Female, β -thalassemia major]

“Each time I have to do blood transfusion, I am worried that I will get infected by HIV, Hepatitis C and Hepatitis B”. [P2, 26 years, male, Malay, β -thalassemia major]

“When he took the supplements, he looked energetic and healthier. I feel that taking the alternative treatments is a way for me to stop him from taking medicines that can be harmful to him because I could see the change and improvements in him”. [P21, 38 years, female, Chinese, carrier]

Most of the participants revealed their deep sense of awareness of their health and implications to their lives. The patients tried to seek other medicines in place of their modern treatment because they were afraid of the side effects of the medicines taken continuously in the future.

Fear of iron chelation therapy

The fear of the side effects of modern treatment was associated with co-morbidities. Many of the participants reported that they had many symptoms and side effects caused by the conventional treatment. The patients felt difficult to comply with the treatment because of the several factors such as side effects and fear of the subcutaneous injection of the iron chelation therapy.

“I vomit frequently after taking exjade and then changed to L1. Injecting dysferal causes my skin to itch. My spleen had been removed. Then I took penicillin. I am easily tired because I have to take injections often. I often tried to escape from getting treatments until I am really not well. If I take medicines, I will sleep all day because the medicines make me feel sleepy. It is very tiring and boring to inject my own self every day and every night. Any alternative treatment, I will try it because I do not want to continue this treatment my whole life and keep on depending on medicines. I do not want it to interfere with my life”. [P15, 24 years, male, Malay, β thalassemia major]

“I swell, itch and hurt each time after injecting dysferal. I take 4 bottles of dysferal each day for 5 days. After blood transfusion I will get a fever. My liver swells up to 8mm. I

need blood. If I do not transfuse blood, I cannot do anything at all. I do not know the exact details of what medicines I took will give what results. Doctor told me to take it and I did. I took the medicines because I feel that it is essential for my disease but I always delay to take the medication. I cannot comply with all medication. I had taken exjade but I vomit each time after taking it. And sometimes, my body will get itchy too”. [P13, 30 years, male, Malay, β -thalassemia major]

“Having injected dysferal 4 bottles a day for 6 days straight sometimes makes me difficult to move and my skin would become itchy”. [P10, 23 years, female, Malay, β -thalassemia major]

“If I take the medicines, I will sleep all day because the medicines make me feel sleepy. It is very tiring and frustrating having to inject oneself every day and every night”. [P15, 24 years, male, Malay, β -thalassemia major]

Fear of surgery

The patients who participated in the study were also afraid about the possibility of them having to undergo surgery and organ removal. They had loss of confidence in the medicines of thalassemia treatment because it failed to treat the illness and some other reasons were provided by the patients to explain why they delayed or avoided getting conventional treatments.

“I had to remove my spleen because it had been swollen due to the continuous blood transfusion done on me”. [P8, female, Malay, β -thalassemia major]

“But if I can get better treatment, for instance the traditional way, I would stop undergoing the treatment I am doing now as I am not sure of its consequences if I continue with this treatment”. [P13, 30 years, Male, Malay, β -thalassemia Major]

“I am worried that my son might have to undergo the spleen removal operation next. My husband and I are worried about the side effects and that is why we strive to look for the best way to heal our child and we have already spent a lot of money to buy supplements rather than depend only on hospital medication”. [P20, 38 years, male, Chinese, carrier]

Positive views about the side effects of modern treatment

Although the patients had some misconception of the conventional treatment, a majority of the participants showed their commitment with the treatment and coped with the general side effects after the treatment; because

they had received the treatment since their childhood and that it was the only means for them to survive.

Their statements seem to suggest that they do not have much choice if they want to continue their lives as normal people.

"I have to undergo all of the treatment in order to live and I have to take the extra supplements to live like normal people". [P2, 26 years, male, Malay, β -thalassemia major]

"I feel that taking medicines is effective. If I do not take the prescribed medicines, I am unable to work especially after having the blood transfusion". [P6, 36 years, female, Malay, Intermediate thalassaemia]

"I believe in the effectiveness of the modern treatment because it works faster compared to the traditional treatment. The cost of conventional treatment is much higher compared to that of the traditional one. The government has spent a lot of money for the thalassaemia patients". [P11, 20 years, female, Malay, Intermediate thalassaemia]

Fear of the symptoms and effects of thalassaemia treatment such as blood transfusion, chelation therapy such as *dysferal* and *exjade* were the main factors that drove patients to find other forms of alternative treatment. However, for the thalassaemia patients, they needed to get the treatment to continue their lives as normal people because the thalassaemia patients were dependent on blood transfusion. The perceptions of the participants was one of acceptance for the fears and side effects because blood transfusion was the mainstay of treatment for individuals with thalassaemia major and many with thalassaemia Intermediate. Patients needed to continue with the modern therapy. However, the side effects of the modern medication and its treatment should be reduced as much as possible and must be supported with proper counselling and social support.

Discussion

The aim of this study was to look into the views of thalassaemia patients regarding thalassaemia, as well as to gain an in-depth understanding of their experiences which are related to modern thalassaemia treatment. The present study represented a diverse group of thalassaemia patients in terms of age, ethnic background and types of thalassaemia. It is the most common chronic and genetic blood disorder in the world.¹¹ Despite the therapeutic efforts, patients would encounter a variety of physical and

physiological problems.¹² Most of the participants admitted having inherited thalassaemia from their parents because of genetic factor. Generally, the probability of people doing screening activities for thalassaemia would be contingent upon how much they found themselves at risk of getting thalassaemia and they would also not know why exactly they have got thalassaemia.

Thalassaemia at present is one of the most challenging haematological disorders with no permanent cure. Patients with the β -thalassaemia major need regular blood transfusions in order to live and the result of iron overload requires chelation therapy. In a developing country like India, the main cause of death from thalassaemia is because of noncompliance with the treatment related to psychological factors.¹³ It can be said that the acceptable and effective ways to avoid cases of thalassaemia are carrier screening and genetic counselling among people with high risks.¹¹ Despite belonging to two different groups of religions, Muslim and Buddhist patients both acknowledged that diagnosis of thalassaemia had brought them closer to God. The patient involved in the study reported various methods of handling thalassaemia. For example, for Muslims patients they coped with it by reciting verses from the Quran, the Holy Book for the Muslims.

The results of the study suggested that the treatment perceptions including fear of side effects may affect patient's decision to use or to forgo modern treatments. The good development of prognosis and the treatment have prolonged the expectation of life among thalassaemia patients. The patients showed a satisfactory level of awareness and knowledge about modern therapy. The patients perceived the modern treatment positively because it had been scientifically proven by research. Based on the interview transcripts, numerous themes emerged with regard to the perceived effectiveness of traditional medicines for thalassaemia. In a study in Turkey, it was found that 1 of every 2 parents of thalassaemia patients had used complementary and alternative medicine (CAM) in treating their children, and mostly had used more than one type of CAM.¹³ Further analysis of the participants could be added on to these perceptions.

In the present study, thalassaemia participants perceived that the modern treatment was effective, despite the high cost of the treatment, and that they would comply with the treatment. Furthermore, fears of the side effects of the treatment such as blood transfusion, iron chelation therapy, surgery and the medication given were also the reasons of noncompliance and delay in seeking treatment. The

complication of iron overload included growth retardation and failure as well as delay in sexual maturation among children. It is also related to complications involving the heart, liver and endocrine glands.¹⁵

Limitation

Because of financial constraint, the study was carried out only in one region in Malaysia. However, serious attempts were made to involve patients ranging from different ethnic, educational and socio-economic backgrounds, and also having different types of thalassemia. These attempts may have helped to generalise the data as much as possible.

Conclusion

This qualitative explanatory study explored thalassemia patients' beliefs and perceptions towards their treatment. Finding comfort in religious practices was found to be useful for patients with thalassemia to cope with their problem. The findings of this study provided some understanding of thalassemia, and the views of thalassemia patients regarding modern treatment, which can be valuable in designing more effective educational and intervention programmes.

Each thalassemia patient's beliefs regarding the treatment they undertake play an important role in persuading them to comply with the treatment diligently, and consistently take their medicines without missing even a single dose since it may bring negative implications. Having a conference or symposium approach may reduce the risk of patients who do not undergo treatment and take their medicines seriously since they would be exposed to the importance of the medicines and treatment undertaken.

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CONFLICTS OF INTEREST

The authors declare that they have no competing interests.

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