

# Complementary and Alternative Medicine Use in Patients with Thalassemia in Malaysia

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## Abstract

**Background:** The aim of this study was to explore the decision-making of patients with thalassemia on the use of complementary and alternative medicine (CAM) via a qualitative approach. **Materials and Methods:** The thematic content analysis of the data revealed a total of four themes: (1) patients' understanding towards CAM; (2) patients' decisions to use CAM; (3) negative views on conventional treatment; and (4) barriers to using CAM. **Results:** The participants mostly defined CAM as traditional medicine or treatment related to herbal medicine. **Discussion:** Those reported to use CAM in favor to encourage the production of blood together with the conventional therapies. The slow progression of CAM modalities and a high cost were the major barriers to use CAM. **Conclusion:** Further investigations are required concerning the effectiveness of using CAM among the patients with thalassemia, and wider knowledge on healthcare education related to this field is required to avoid any harmful interaction due to the combination of conventional and CAM therapies.

**Keywords:** Complementary and alternative medicine, Malaysia, qualitative, seeking treatment, thalassemia

## INTRODUCTION

The use of complementary and alternative medicine (CAM) is increasing worldwide and is widespread in developing countries including Malaysia. Recently, the use of CAM has been extended to developed countries.<sup>[1]</sup> The CAM usage was high, with 70.2% of patients at risk of or diagnosed with hematological cancer in Malaysia using CAM for their problem.<sup>[2]</sup> Although the use of conventional medicine is prevalent, CAM is still used in many countries including Malaysia and has made a significant contribution to the health care of the Malaysian community. A previous study has found that the prevalence of CAM use among Malaysians in their lifetime was 69.4% and the use of CAM in the form of biologically based therapy for health problems was 88.9%.<sup>[3]</sup> The National Policy of Traditional and Complementary Medicine, which has been introduced in Malaysia since 2007, states that the traditional or complementary medicine system shall be an important component of the healthcare system.

Thalassemia is the most common single-gene disorder in the world with an estimated 266 million carriers of thalassemia and 60,000 people with major thalassemia (WHO, 2011).<sup>[4]</sup> In Malaysia, it is estimated that 6233 patients are registered in the Thalassemia Registry, of which, 4463 patients are on regular blood transfusion and iron chelation treatment. About 200 cases are added to the registry each year. It is anticipated

that every new patient can survive up to 30 years.<sup>[5]</sup> The conventional treatment for patients with thalassemia is regular blood transfusion and iron chelation therapy. It is very important that the patients follow the treatment. Otherwise, non-compliance will lead to endocrine, cardiac or hepatic disorders, or a combination of them.<sup>[6]</sup>

Elsewhere, limited studies have been reported on the use of CAM among patients with thalassemia. For example, in Turkey, 82.5% of the parents use one or more CAM to treat the health problems of their children having thalassemia.<sup>[7]</sup>

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Thalassemia is considered a major cause of morbidity and mortality worldwide because there is no cure available for the severe form of thalassemia. Moreover, patients with thalassemia have to endure treatments due to toxic iron that accumulates proximately in the red blood cell of the major organs, wherein dysregulated iron absorption occurs and can potentially be fatal throughout the tissue to the blood transfusion intended to treat them.<sup>[8,9]</sup> Hence, it is not unusual that the practice of using non-conventional medicine such as traditional and complementary medicine is adopted. The aim of this study was, therefore, to determine the decision-making of the patients with thalassemia on the use of CAM for the management of their health care.

## MATERIALS AND METHODS

Ethical approval was obtained from the Committee of School of Pharmaceutical Sciences Universiti Sains Malaysia-Hospital Lam Wah Ee (USM-LWEH [reference: USM-HLWEH/IEC/2015 (002)]) prior to the commencement of the study. The recruitment of the participants was made by the principal investigator through patient support groups. The participants of the present study were selected among patients aged 18 years or older who had been diagnosed with thalassemia. The participants were provided with written informed consent forms, which were returned to the principal investigator. Semi-structured, in-depth interviews, which lasted approximately 45–60 min, were conducted using the Malay language. The interview sessions were digitally recorded and transcribed in English by the principal investigator. After an extensive literature review, a list of possible questions covering the main themes of the study was generated. Open-ended questions were used to provide maximum opportunity for the participants to express their views.

The questionnaire is usually piloted to detect potential problems and help the researcher in matters associated with the recruitment of patients in research to ensure that it can and should be conducted appropriately or in the modification of the questionnaire if necessary.<sup>[9,10]</sup> In the present study, the questionnaire used was piloted with five patients with thalassemia to determine whether the questionnaire was appropriate for use and that no changes would be made after the pilot study was completed.

### Study participants

The study was conducted from July until October 2015 at Kedah Thalassaemia Society Centre in Alor Star, Kedah, situated in the northern region of Peninsular Malaysia. To ensure the diversity of perceptions and beliefs regarding the use of CAM, the patients were purposely selected across age, sex, ethnicity and educational background. Interviews were conducted with 21 patients with thalassemia, who were recruited among the society members to participate in this study by the principal investigator through patient support groups of Kedah Thalassaemia Society Centre. All

participants were provided with informed consent forms after they were briefed about the purpose of the study. The participants were assured that the information would remain confidential and would not affect their future treatment. The interview sessions continued until the saturation point when no more new information could be obtained from subsequent interviews. To ensure their privacy and for the purpose of anonymity, each patient was given a number (e.g. P01–P21). Although the interview sessions were conducted in Malay language; English language was also used for the patients who preferred to communicate in both languages. The principal investigator was present during the entire interview session. The interview transcripts were then prepared, reviewed, and sent to the participants for approval. Interviews were recorded thematically, which involved coding and identification of common or recurrent themes using the comparative analytic process of each of the participants' views.<sup>[10,11]</sup> All the common themes were later discussed with independent researchers and identified after numerous repeated readings to ensure the reliability and accuracy of the data.<sup>[12]</sup> For this study, purposive and theoretical sampling techniques were combined to explore the issues related to the use of CAM among patients with thalassemia.<sup>[13]</sup> The patients were purposively sampled among three major ethnic groups in Malaysia, namely, Malay, Chinese, and Indian. Recruitment was made until theoretical saturation was reached, meaning no new information would emerge after subsequent interviews, thus fulfilling the theoretical sampling requirement.<sup>[14]</sup>

## RESULTS

The patients' demographic data and disease characteristics are summarized and presented in Table 1. None of the participants who had been diagnosed with thalassemia were medically insured, and government hospitals were their only place for treatment. Nineteen patients identified themselves as CAM users, whereas three patients stated that they had not used CAM since they had been diagnosed with thalassemia. The most common type of therapies used was biologically based therapy including dietary or vitamin supplements, followed by herbs and folk remedies. Mind-body interventions were also used among patients with thalassemia. The majority of patients used prayers as a form of treatment. There were patients with thalassemia who used Malay traditional medicine and a few who used body-based

**Table 1: Demographic and clinical characteristics of the participants**

Characteristics	N=21	%
Age (mean = 29)		
18–30	13	62
31–40	7	33
41–50	0	0
51–60	1	5
Gender		
Male	6	29
Female	15	71

Race			
Malay	17	81	
Chinese	4	19	
Religion			
Islam	17	81	
Buddhism	4	19	
Educational status			
Primary	2	10	
Secondary	12	57	
Diploma/matriculation	7	33	
Socio-economic status*			
Low (less than RM 1000/month)	13	62	
Middle (RM 1000–3000/month)	8	38	
High (>RM 3000/month)	0	0	
Medical insurance			
Yes	2	10	
No	19	90	
Marital status			
Single	13	62	
Married	7	33	
Divorce	1	5	
Type of thalassemia			
β thalassemia major	13	62	
Intermediate thalassemia	6	29	
Thalassemia minor (trait)	2	10	

\*Sources: Department of Statistic Malaysia, Official Portal 2015.

method by massage therapy. Furthermore, some of the patients also tried using a whole medical system such as homeopathy. Nevertheless, some patients with thalassemia were initially reported to have rejected conventional treatment using modern medicine in favor of traditional therapies during the early stage of the diagnosis of the disease. It was difficult for most of the patients to comply with the treatment provided in the hospital. Only a few patients complied with all the medications. These patients felt worried and tried to treat the adverse effects caused by conventional treatment. The patients claimed that they had the intention to find any traditional treatment or CAM that could help relieve them of their disease.

The thematic content analysis of the data revealed a total of four themes: (1) patients' understanding towards CAM; (2) patients' decisions to use CAM; (3) negative views on conventional treatment; and (4) barriers to using CAM [Table 2].

Table 2: Analysis matrix	
Themes	Sub-themes
Patients' understanding towards CAM	Medicines from natural sources
Discussion on CAM	Having own opinion on CAM
	Role of health practitioners in decision-making on the use of CAM
	Role of friends and family members in the decision-making on the use of CAM
Reasons for CAM use	The use of CAM for co-morbidities

	associated with thalassemia
	The use of CAM to treat emotional and psychological symptoms
Negative views on conventional treatment	Perceived ineffectiveness of CAM for thalassemia
Barriers using CAM	Lack of money

### Patients' understanding of CAM Medicines from natural sources

The purpose of this investigation was to evaluate the patients' definition of the use of CAM to reduce the symptoms of thalassemia disease. The participants mostly defined CAM as traditional medicine or treatment related to herbal medicine. Very few patients understood the meaning of the term CAM. Many of them asked for clarification of the word CAM because they were not familiar with the term since CAM could be anything one does for one's health not prescribed or recommended by one's doctor.

'CAM is herbal medicine like "ulam-ulaman" [herbs] and any home remedies' (P2, 26 years, male, Malay, β thalassemia major).

'CAM is something that you use from the kitchen and is very easy to find' (P4, 24 years, female, Malay, β thalassemia major).

Some of the patients viewed CAM therapies as having slow responses compared to conventional treatment, whereas most patients believed that CAM therapies used medicines from herbs or trees.

'I feel and believe that modern treatment works for those with Thalassemia. It responds faster compared to traditional treatments. The modern treatment is proven with so many research studies and it has already been tested before the drug is used' (P7, 29 years, female, Malay, intermediate thalassemia).

'CAM is only a supplement and cannot cure the thalassemia disease because thalassemia is a genetic disease' (P9, 19 years, female, Malay, β thalassemia major).

### Discussion on CAM Having own opinion of CAM

Most patients with thalassemia used CAM because they were worried about the effects and effectiveness of conventional treatment. They believed that traditional treatments such as those that involved emotional and spiritual therapies were safe for them.

'I took holy drinks like those from Darul Syifa [spiritual practitioners], which were given to me by my family' (P4, 24 years, female, Malay, β thalassemia major).

'To calm myself and bring myself to accept the fact that I carry this disease, I do a lot of "solat Tahajjud" [voluntary night prayers] and "zikr" [remembrance of God] and they make me become closer to Allah Subhanahu wa Ta'ala [The Almighty]' (P12, 32 years, female, β thalassemia major).

'When I was a baby, [I was told that] my parents often gave me holy waters, which they had taken from many "Ustazs" [spiritual practitioners] in Kedah' (P17, 22 years, female, Malay,  $\beta$  thalassemia major).

Some patients identified that the psychological effect was something described as related to feelings. Some of the patients chose to go to bed and listen to music for relaxing rather than get a blood transfusion treatment.

'I often go to bed and listen to music when the symptoms of low blood levels appear and it helps me relax and relieve me of the tiredness' (P15, 24 years, male, Malay,  $\beta$  thalassemia major).

### Role of health practitioners in decision-making on the use of CAM

Communication between the patients and the health practitioners, whether modern or traditional, is very important so that the patients know about the medication they are taking. Some patients tried to discuss their use of CAM with their physicians and seek advice about it.

'I usually ask the doctor to give his opinion about some of the CAM I took, so that he knows because I want to be sure that it is not going to interfere with my other modern treatment' (P1, 38 years, female, Malay, intermediate thalassemia).

However, due to the perceptions held by the patients that the medical staff members would disapprove of the use of CAM and that it might affect the subsequent treatment given to them, many of the patients decided not to discuss their use of CAM.

'I took supplements without the doctor's knowledge while I was on [conventional] medicines. I am afraid that the doctor would tell me off' (P2, 26 years, male, Malay,  $\beta$  thalassemia major).

### Role of friends and family members in decision-making on the use of CAM

Friends, family members, and other thalassemia survivors played an important role in decision-making on the use of CAM.

'I tried whatever supplements that my parents recommended. Now I am trying fruit juice product to see the effectiveness of it in generating blood' (P9, 19 years, male, Malay, intermediate thalassemia).

'My family looked for healing solutions from an "Ustaz" [spiritual practitioner] by taking holy water' (P7, 29 years, female, Malay, intermediate thalassemia).

### Reasons for focusing on CAM

The patients gave a few reasons for using CAM, namely to avoid co-morbidities, fight against symptoms of thalassemia, and reduce medication intake.

### Use of CAM for co-morbidities associated with thalassemia

Most of the patients using CAM were associated with thalassemia illness and its treatment.

'I had my spleen removal when I was 4 years old and have been taking penicillin continuously ever since. I am not sure of the effects on me, so I use CAM like honey and herbs to help boost my immunity' (P4, 24 years, female, Malay,  $\beta$  thalassemia major).

'I do consume a lot of traditional remedies. They are "daun belalai gajah" [Sabah Snake Grass], Chinese herbal tea, eel soup, and lady's fingers. All of these are able to generate more blood' (P5, 22 years, female, Malay,  $\beta$  thalassemia major).

Most of the participants used CAM to treat hormone imbalance, which could cause osteoporosis and infertility.

'I take extra supplements such as goat milk and honey to stabilize my hormones because I want to have kids' (P1, 38 years, female, Malay, intermediate thalassemia).

'I took supplements such as calcium tablets and cow's first milk for my bones to prevent osteoporosis' (P7, 29 years, female, Malay, intermediate thalassemia).

'I never had a period until I went on the pills. I was about 16 years old when I first took the pills' (P1, 38 years, female, Malay, intermediate thalassemia).

### Use of CAM to treat emotional and psychological symptoms

The patients used CAM to relieve their depression, anger, and pain. Most of the patients also used CAM to treat associated emotional and psychological symptoms to enable them to continue receiving treatment in hospitals because the course of treatment lasted very long and this made them feel bored and tired of it.

'I took extra supplements together with the medicine. I need to be healthy like others because I have to look after my kids and family' (P8, 31 years, female, Malay, intermediate thalassemia).

'After I take the medicine, I feel tired and sleepy, so I need extra supplements to give me the energy to look after my kids, cook, do house cleaning, and I want to live like normal people' (P16, 26 years, female, Malay,  $\beta$  thalassemia major).

The patients also used CAM to treat psychological symptoms to manage and overcome stress and negative feelings of themselves.

'When I feel depressed and tired with all the medication, I do lots of additional prayers and recite the Qur'an to calm my own self' (P10, 23 years, female, Malay,  $\beta$  thalassemia major).

'For therapy, I read motivational and religious books to give me motivation, hope, and faith. I love listening to Islamic music. I feel calm' (P12, 32 years, female, Malay,  $\beta$  thalassemia major).

### Negative views on conventional treatment perceived the ineffectiveness of CAM for thalassemia

The patients used CAM to overcome the effects of the use of conventional medicine. They used CAM because conventional medicine failed in treating the recurring illness. They also used CAM to minimize health crises and reduce the time spent in the hospital.

'I just took CAM to stop from catching the illness. I tried to find other medication rather than depend on medicine given by doctors' (P6, 32 years, female, Malay, intermediate thalassemia).

CAM was used by the patients, because the medication given to them failed to prevent infections and, therefore, the patients tried to find other ways to strengthen their immune system.

'Each time I take my exjade, I feel weak and I would be unable to do many works. I do not know exactly what type of effect the treatment will have on me. I also take CAM because my spleen was taken out and the doctors gave me penicillin but it didn't work. So, I take other alternative medicines to help me' (P2, 26 years, male, Malay,  $\beta$  thalassemia major).

Many of the patients used CAM because conventional treatment was insufficient to maintain good health.

'I often feel angry because I take many medicines and they are not effective. I am still sick and get infected. So, I take additional supplements to help [protect] me from getting easily infected' (P3, 31 years, female, Malay, intermediate thalassemia).

All the conventional treatments have their own effects on me. As an example, at the beginning of the blood transfusion, I had fever very often and experienced chills after that because, at that time, the blood transfusion had no filter as of now. Taking desferal caused me down with fever and LI led to nausea and vomiting. To prevent this, I replaced them with traditional remedies and took supplements to avoid the side effects of the medication' (P7, 27 years, female, Malay, intermediate thalassemia).

'After taking the modern treatment, the increase in blood caused my skin to be itchy and I was down with a fever after receiving the blood. Besides that, my spleen also swelled up to 9 cm and my liver swelled up to 4 cm. I was worried that I might have been infected with HIV when receiving the blood. Now I try to use CAM like stem cell product to see if it is

effective in generating blood' (P9, 19 years, female, Malay, intermediate thalassemia).

Many patients reported that using conventional treatment was a never-ending cycle of illness and treatment.

### Barrier to using CAM Lack of money

Many patients acknowledged the advantages of using CAM. The patients would carry the illness from cradle to the grave. It was discovered that none of the patients with thalassemia were medically insured, and the conventional treatment was covered by the hospitals. The patients who want to use CAM for treatment have to spend their own money on it. Those who started using CAM initially were unable to continue the treatment for long because of financial problems.

This was a key issue among the patients because many participants were unemployed, self-employed or employed on a short-term contract with no healthcare insurance cover.

'For my child with  $\beta$  Thalassemia Major, I bought him extra supplements such as Kangen from the ELKEN products, which is believed to be able to generate more blood. We spent RM 2000 for 5 months. But we stopped because we could not afford to continue the supplement. I saw the difference when my child took that supplement' (P20, 39 years, male, Chinese, thalassemia carrier).

'I used homeopathy for more than 3 years, but suddenly I had to stop because of the financial crisis and now I only continue with traditional remedies' (P6, 32 years, female, Malay, intermediate thalassemia).

'I took one nutritional supplement of cow's first milk tablets. It helped, but the price, which was too expensive, made me stop taking it' (P9, 19 years, female, Malay, intermediate thalassemia).

## DISCUSSION

This study reports CAM use among patients with thalassemia in Malaysia and is mainly based on the perception of patients without regard for the clinical reality, which relates to characteristics, rationale, mode of action, therapeutic results of CAM and the effects of its use.

The results in this study showed a similar trend of CAM use throughout the world<sup>[1,7,15,16]</sup> and in Malaysia.

Other studies had shown the consistency of biomedicine together with conventional medicine, especially on patients with chronic diseases.<sup>[2,10,16]</sup> The participants in the present study described CAM therapies such as home folk remedies, herbal medicine, and spiritual therapies, a trend, which had also been reported in the literature.<sup>[10]</sup>

The patients with thalassemia who were interviewed in this study were found to have used traditional Malay medicine, meditation, traditional Malay massage, dietary supplements, and spiritual therapies as CAM. Previously, only one study was related to children with thalassemia, and the result indicated that 82.5% of the children had used CAM. In this

study, it was interesting to explore the reasons for using or not using CAM in patients who must adhere to conventional medication to survive for their entire lifetime.

The patients with thalassemia used CAM to improve their quality of life, reduce the side effects of modern medication, lower the risk of death and serious complications to the body, such as abnormalities caused by thalassemia. A qualitative investigation regarding the cause of thalassemia among the patients with thalassemia found that the fear of symptoms and side effects of thalassemia treatment drove patients to find other alternative treatments.<sup>[17]</sup> A qualitative study, conducted in South Trinidad reported that the patients using CAM had improved their quality of life because holistic care had been provided to them. As reported in the previous studies<sup>[2,10,16]</sup> spiritual ways of healing helped to overcome the patients' emotional problems and subsequently enabled them to lead a normal life instead of just thinking of the effects and consequences that they would face. Another significant factor was that the patients who used spiritual therapies were patients with thalassemia major and intermediate thalassemia. It was also noted that most patients used spiritual therapies because of their low cost compared to other therapies.

It was found that electronic medical resources, friends, family members, healthcare providers, and other thalassemia survivors had played an important role in making a decision on the use of CAM. Communication with health practitioners was crucial in the decision-making process. In a previous study, the patients reported having placed their trust in their healthcare providers in asking or seeking opinion about the CAM they would like to take.<sup>[16]</sup> However, the lack of interest in CAM therapies among the physicians and patients' worries about the discontinuation of the conventional treatment made the patients decide not to disclose their use of CAM. In another previous study, 61.9% of the healthcare providers responded that their knowledge of CAM was limited and they had little experience with CAM; however, they were interested in CAM modalities.<sup>[18]</sup>

Therefore, it is vital for healthcare providers to get more knowledge about available therapies so that they could give appropriate advice, which would be advantageous to the patients' physical and spiritual well-being. Pre-conception among the patients also influenced non-disclosure of CAM, because they were afraid that they might not be allowed to continue receiving the conventional treatment. The patients' personal experience in consulting their doctors limited them in asking for an opinion about CAM.<sup>[19]</sup> In this study, the patients felt afraid that the treatment by the physicians would be terminated and this was the key reason why the patients did not personally disclose their use of CAM. In Malaysia, 88.9% of the patients are known to commonly use CAM for their health problems.<sup>[3]</sup> It is important that the physicians initiate an open discussion with their patients regarding CAM use to prevent possible complications in the interactions between conventional medicine and CAM. It has been cited

in the literature that incorrect prescription of vitamin C or its prescription in higher doses for the patients can increase the toxicity of iron.<sup>[20]</sup> A previous study indicated that 63.9% of patients with chronic disease use CAM, normally alongside modern medication and not merely as an alternative treatment.<sup>[1]</sup>

The patients' decisions on the use of CAM depended largely on their interpretation and understanding of CAM. Many of the participants shared their views on using CAM to treat thalassemia major as well as to reduce mortality rate, side effects of conventional therapies, and the symptoms related to thalassemia. The participants claimed that they used CAM to prevent the effect of the medication they had been taking on a long-term basis, namely since birth until the present time, a duration of almost 20-30 years. This prolonged use of medication to treat thalassemia, unfortunately, caused comorbidities. The participants had their own perceptions regarding conventional medicine and the use of CAM as a treatment.

Financial constraints were identified as barriers to using CAM. The patients were found to have no medical insurance that could cover for thalassemia. This had caused more patients with thalassemia to use CAM compared to patients with other diseases. Nevertheless, it was found that the patients had to stop using CAM therapies because they could no longer bear the cost. Even though the Malaysian healthcare system gives free treatment for many ailments and diseases, it does not cover the traditional treatment. It can be concluded that the demand for complementary medicine from the public has risen to the extent that there should be communication and cooperation among stakeholders, members of the public, and conventional and traditional practitioners, so that the public could get accurate information regarding the efficacy and safe use of CAM alone or the combination of CAM and conventional medicine.<sup>[10,21]</sup>

## Limitations

There were some limitations in this study. The study did not include an adequate number of participants from all ethnic groups in Malaysia because it only included the patients who were Chinese and Malay. Finally, the data also showed that the majority of the participants were from the low-income group.

## CONCLUSION

The use of CAM is prevalent among the patients with thalassemia, and wider knowledge on healthcare education related to this field is required to avoid any complications that could arise due to the combination of conventional and CAM therapies. The patients with thalassemia use CAM therapies to improve their well-being and quality of life. Associated factors identified were family members, friends, and others,

which included the media, CAM providers and positive testimonies from other patients.

This study offers insights into the ways in which small groups of patients with thalassemia underwent their therapies. The patients were willing to use CAM but they were also unwilling to discontinue using conventional medicine. Nevertheless, the use of CAM together with conventional medicine may pose a major public health concern. Hence, there is clearly a need for further research in this field.

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### Conflicts of interest

There are no conflicts of interest.

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