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Patient Beliefs and Motivations for Adopting Biologically-based Therapies in Thalassemia Management in Malaysia

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Abstract
Herbs, vitamins, and supplements mitigate chronic conditions like thalassaemia, a genetic blood disorder that compromises mental and physical health. These rituals are prevalent; yet, the reasons of Malaysian thalassaemia patients remain ambiguous. We evaluated healthcare accessibility, motivations, perceived benefits, and the interactions between physicians and nurses among 390 individuals in Northern Malaysia. The figures indicate that individuals employ it for its health benefits, cultural beliefs, and preference for traditional remedies. Patients rarely engage in communication with clinicians. Healthcare providers and patients must understand each other's cultural situations.

Keywords: Thalassemia; Biologically-based Therapies; Patient Beliefs

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1.0 Introduction

Thalassaemia is a long-term, inherited blood disorder that makes it hard for the body to make haemoglobin. It causes anaemia for life and needs medical care. People with thalassaemia, especially those who need transfusions, may have physical and mental health problems since they have to have regular blood transfusions, iron chelation therapy, and other medical procedures. Patients and caretakers often turn to complementary and alternative medicine (CAM) to feel better because of these problems.Herbal medications, nutritional supplements, and animal goods are all examples of BBTs, a major type of CAM. In Malaysia, where many cultures live together and traditional medicine is critical, BBTs are often utilised to treat long-term conditions like thalassaemia. Even though it is popular, there hasn't been enough research on how BBT is used, what people believe about it, and why they use it in thalassaemia

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care. Studies show that people with thalassaemia often take herbal teas to help with spleen problems. BBTs that improve immunity and strength include goat milk, spirulina, and extracts from freshwater oysters (Abdul Wahab et al., 2011).In Malaysia, 82.5% of people with thalassaemia used CAM. Of those, 47.4% used nutritional supplements and 35.1% used animal products. The main reasons people used CAM were to improve their child's health, immunity, and comfort, as well as to reduce side effects and improve conventional treatment (Efe et al., 2013c). Demographic characteristics, especially lower education, can help predict CAM use among parents of children with thalassaemia. People frequently utilise BBTs and other CAMs in addition to medical therapy. There are doubts about how it affects treatment adherence. Researchers discovered that using both traditional and alternative medicine made people less likely to go through with iron chelation therapy, which raised worries about harmful effects (Lee et al., 2011). Cancer patients in Malaysia have also used BBTs. In fact, 90.5% of them employed CAM to improve their physical and overall health (Dhanoa et al., 2014b). There are several reasons why it's vital to know why thalassaemia patients utilise BBTs and how they feel about them. First, using CAM without telling your doctor can lead to drug interactions and make traditional treatments less effective. Second, not being able to talk openly with doctors and patients about CAM use could hurt trust and the willingness to take medication. Third, learning about the cultural and motivational factors that lead to CAM usage could help design care models that are more culturally sensitive and focused on the patient, and that reflect their values and experiences.

2.0 Literature review

Biologically-based therapies (BBTs), a subset of complementary and alternative medicine (CAM), include herbal remedies, nutritional supplements, animal products, and other natural substances. These therapies are commonly used alongside conventional treatment for chronic illnesses such as thalassemia. Among thalassemia patients in Malaysia, the use of CAM including BBTs is widespread, driven by various cultural, emotional, and health-related motivations (Ngoo et al., 2018).In a cross-sectional Malaysian study, 82.5% of thalassemia patients reported CAM usage, with 47.4% using nutritional supplements and 35.1% consuming animal-based products such as goat milk and freshwater oysters (Abdul Wahab et al., 2011). The motivations included relieving treatment-related discomfort, boosting immunity, improving overall well-being, and complementing conventional treatments. However, this study grouped all CAM modalities without isolating BBT-specific patterns, highlighting a limitation in understanding biologically-based therapy usage specifically. Another study by Ngoo et al. (2018) reinforced that CAM use among thalassemia patients was significantly influenced by non-clinical factors, such as recommendations from family and friends, cultural practices, and ease of access. Importantly, many patients used CAM covertly due to fear of negative reactions from healthcare providers, which hindered open discussions about potential interactions between conventional and complementary treatments.

In addition, psychosocial factors such as emotional coping, belief systems, and perceived trust in the healthcare system appear to significantly influence patients' decisions to adopt BBTs. Phang et al. (2021) conducted a qualitative study in Malaysia and found that thalassemia patients often grapple with psychological stress, treatment burden, and a desire for more autonomy in managing their condition. These emotional and cultural beliefs, though not always linked directly to BBT use, provide critical context for understanding patients' motivations.

From a health economics perspective, the high financial burden associated with conventional thalassemia care, particularly regular transfusions and iron chelation therapy may also drive patients toward alternative or supplementary options. Wong et al. (2021) estimated the lifetime cost of managing transfusion-dependent thalassemia in Malaysia to be approximately USD 606,000 per patient. Such economic considerations may motivate patients to seek more accessible or affordable biologically based interventions.

Despite the high prevalence of CAM usage, there is a notable lack of specific research on BBT use among thalassemia patients in Malaysia. Existing studies often aggregate BBTs with other CAM modalities, such as spiritual healing or manipulative therapies, without providing detailed analyses of biological-based therapy patterns. Furthermore, few studies have examined how socio-demographic variables, such as ethnicity, education level, and income influence BBT adoption. Similarly, there is minimal empirical research on how psychological constructs (e.g., health beliefs, emotional regulation, and cultural identity) shape BBT usage in chronic disease management.

The lack of communication between healthcare providers and patients regarding BBT use presents another significant barrier. Lee et al. (2011) observed that some patients delayed or discontinued iron chelation therapy due to simultaneous use of traditional or complementary treatments, sometimes without informing their physicians. This highlights the importance of culturally sensitive, open dialogue in clinical encounters.

Given the evident gaps in the literature particularly regarding BBT-specific patterns, motivations, and patient–provider communication this study is timely and necessary. It aims to explore the prevalence of BBT use among thalassemia patients in Northern Malaysia, their motivations for adopting these therapies, and how socio-demographic and psychosocial factors influence these practices. Understanding these dimensions can contribute to more effective, culturally congruent chronic disease management strategies.

3.0 Methodology

3.1 The design and location of the study

This study used a cross-sectional quantitative design to investigate thalassaemia patients' opinions, reasons for using, and biologically based therapies (BBTs) patterns. The study occurred in government hospitals in the Northern part of Peninsular Malaysia, with many thalassaemia patients getting continued care at specialised haematology clinics.

3.2 Participants and Sampling

Between July and October 2014, 390 patients with thalassaemia were recruited from Haematologic clinics, day care facilities, and the centre of the Kedah Thalassaemia Society using purposive sampling. To be eligible, you had to: (1) have a confirmed diagnosis of thalassaemia (major or intermedia), (2) be 18 years old or older, (3) be getting treatment at one of the selected government institutions, and (4) be able to read and fill out the questionnaire in Malay or English. People who had cognitive problems or serious health problems that made it hard for them to talk were not allowed to participate. We used Cochran's calculation for proportions with a 5% margin of error and a 95% confidence level to figure out how many people we needed to sample. We also considered how everyday CAM use is in similar groups.

3.3 Tool for Collecting Data

We gathered data using a structured, self-administered questionnaire that was based on a study of the literature and procedures that have been shown to work in previous studies (e.g., Abdul Wahab et al., 2011; Efe et al., 2013c; Dhanoa et al., 2014b). There were five main parts to the instrument:

1. Age, gender, race, level of education, job, income, and type of thalassaemia are all part of the sociodemographic profile.
2. Biologically Based Therapies: What kinds of BBTs are utilised (such as herbs, vitamins, and animal products), how often they are used, and where people get information about them.
3. Reasons for utilising BBTs include how well they think they work, cultural or family influences, and satisfaction.
4. Possible Benefits and Side Effects: Physical, emotional, or symptomatic results.
5. Talking to doctors: telling them about BBT use and the reasons for telling or not telling.

30 thalassaemia patients were not part of the final sample who were given the questionnaire before it was sent out to ensure it was clear, reliable, and culturally appropriate. Some little changes were made depending on what people said. For essential constructs, Cronbach's alpha coefficients for internal consistency were higher than 0.80, which means they were reliable.During regular clinic visits, the researchers talked to the participants and gave them much information about the study. After providing written informed consent, individuals filled out the questionnaire in a designated waiting room or at home. Individuals could then return the completed form at their next appointment or by mail.

3.4 Analysing Data

We used IBM SPSS Statistics version 22 to look at the data. We employed descriptive statistics, including frequencies, percentages, averages, and standard deviations to summarize the sociodemographic traits and patterns of BBT use. We used chi-square tests to examine the links between BBT use and specific categorical characteristics, such as gender, ethnicity, and educational degree. We fixed the level of statistical significance at $p < 0.05$.

3.5 Ethical consideration

The School of Pharmaceutical Sciences, USM, and Lam Wah Ee Hospital on Clinical Studies in Malaysia's joint ethical committees approved the study (reference: USM-HLWE/IEC/2015 (0002)). Participants were told that their information would be kept private, that they could choose to take part, and they could leave at any moment without impacting their medical care.

4.0 Findings

Table 1.0: Types of Biological Based Therapies (BBTs) used by CAM users

BBTs categories	CAM Users N=268 n (%)
Nutritional Supplements Goat Milk, Herbal life Nutri supplements, Honey, Shaklee supplements, Cell food, Green tea, Alkaline water, Garlic Tablet, Stem Cell Apple, Zinc Supplements, Fish Oil, Grape seed extract, Gingko, Ginseng, Ginger, Vitamin C, Turmeric, For Life Milk, B17 apricot seed, spirulina, Probiotics, E, B12, Folic acid, calcium, wheatgrass.Thistle and weeds, Fruit juice PLUS 7, Elken, Geoderma.Habatussauda	174 (64.9)
Special Diets Black tea, parsley, lemon, grape, quail eggs, wild honey, Traditional jamu, *Sea cucumber[1], *Soursop[2], Coconut water, pomegranate juice, palm juice, clam meat, chicken egg, *Sabah snake grass3, Spinach juice, lady fingers, horse milk, *Prickly leafed, royal jelly, bitter gourd, eels, cockles, liver, Grape molasses	94 (35.1)

Local name

1. *Gamat*
2. *Durian Belanda*
3. *Belalai gajah*
4. *Daun tutup bumi*

A total of 390 patients were involved in this study. Of the 390 patients interviewed, 313 (80.26%) had used CAM for their condition. The respondents' mean age (SD) was 25.40 (±10.2) years. Respondents mainly consisted of women, and there were 221 (56.67%). Most respondents are Malay 361, 92.56%) and nearly all respondents 357 (91.54%) practice Islam as their religion. Also, most respondents have a secondary level of education 256 (65.64%). Most respondents were unmarried 204, 52.30%), and 129 (33.1%) were unemployed. One hundred sixteen (29.74%) respondents had a monthly income of less than RM1000, and 53 (13.59%) were unemployed. Mostly, respondents did not have medical insurance 282, 72.3%).

The types of BBTs were further subdivided into two categories i.e. nutritional supplements and special diets (Table 1.0)

4.1 Disease characteristic of the users for different types of CAM therapies

BBTs users show a significant difference where type β-Thalassemia Major ($p<0.001$), duration of disease for more than 5 years ($p<0.001$), received treatments in the form of surgery ($p=0.03$) and iron chelation therapy ($p=0.01$), with a history of side effects due to conventional treatment.

5.0 Discussion

The prevalence of BBTs among thalassemia patients was 85.62%. The BBTs are the second-highest usage of the CAM among patients with thalassemia. We found that the patients with thalassemia mostly like to consume vitamin-based nutritional supplements (64.9%) to boost their health. The current study reveals a higher percentage than in the previous study, which was only 47.4% of nutritional supplement use. And most of those using CAM are patients in the middle-income bracket of RM1000-RM3000. Without knowing the side effects, thalassemia patients continue to take it because they are looking for a cure for their illnesses. A previous study showed that using vitamin E can help prevent tissue damage from oxidative stress, causing iron accumulation in the body (Rashidi et al., 2011). However, if BBTs' CAM is not controlled, it will affect the patient's health. Previous studies showed that side effects for such alternative treatment may increase the iron accumulation (Carvalho et al., 2001) because of the self-prescribing without ample knowledge of how the doctor prescribed such supplements, intake of vitamins, minerals, vitamin C, and iron can lead to heart risk (M.-D. Cappellini et al., 2008). Vitamin C is usually present in most foods taken daily, and those given by a doctor are to improve iron chelation. Still, DFO intake causes an increase in iron toxicity in tissues, but when taken in excess, it may cause iron accumulation in the heart (M.-D. Cappellini et al., 2008).

Apart from that, the use of the ginseng (Panax ginseng), garlic (Allium sativum) or ginkgo (Ginkgo Biloba) in conjunction with conventional medicines such as wafarinn and aspirin that are common to thalassemia patients can cause blood accumulation in the body (Fugh-Berman, 2000) and can lead to death risk because of blood coagulation at more than the desired level (Miller, 1998). These substances have anticoagulant effects.

The current study, supported by previous studies, showed that the pomegranate intake by patients with thalassemia can improve and prevent anemia. Parents of children with thalassemia provide their children with molasses or pomegranate to avoid anemia, but excessive intake can cause iron accumulation in the blood (Efe et al., 2013). However, other findings show good antioxidant activity (46.31%) and contain iron (1.05-22.99 mg / 100g). Due to this, thalassemia patients are advised against taking pomegranate frequently in large quantities to prevent iron accumulation in their blood (İncedayi et al., 2010).

Furthermore, taking special diets that consist of herbs such as sea cucumber, prickly leaf, Sabah snake grass, and animal materials such as cockles, eels, wild honey, and liver among 35.1% thalassemia patients because they believe those can help them in the healing process and reduce other symptoms and detrimental side effects of the consumed medicine. Current study found that the use of wild honey among thalassemia patients, and previous studies show the benefits of administering honey for treatment because it can increase serum antioxidant, vitamin C concentration, beta-carotene, and glutathione reductase, and honey also can help to reduce plasma ferritin by 11% and improve immune system (Al-Waili, 2003; El Sayed et al., 2014). Thalassemia patients are using CAM mostly because they feel CAM is natural and has no side effects. In the current studies, only 11.5% mention that CAM has side effects. Previous studies have also supported the idea that the use of CAM is safe and natural (Efe et al., 2013).

Due to the prevalence of use among thalassemia patients, extensive studies should be done to avoid drug interaction with CAM that can potentially have fatal implications.

6.0 Conclusion& Recommendations

This study reveals a high prevalence (85.62%) of biologically based therapy (BBT) use among thalassemia patients, particularly vitamin-based supplements, often perceived as natural and safe. However, unregulated use poses risks such as iron overload and adverse interactions with conventional treatments like iron chelators and anticoagulants. Despite these risks, awareness of side effects remains low. Future research should focus on evaluating the long-term safety and efficacy of commonly used BBTs, investigating their interactions with standard therapies, and exploring patients' cultural and psychological motivations. Culturally tailored education and

clear communication between patients and healthcare providers are essential to ensure safe and integrated care in thalassemia management.

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Paper Contribution to Related Field of Study

This study is about the primary cultural and motivational reasons why Malaysian thalassaemia patients adopt biologically based therapy. It fills a gap in CAM research for this group of people and highlights how vital it is for patients and clinicians to communicate clearly. The results show that we need to find more culturally sensitive and integrated ways to treat chronic diseases. They can also assist influence future healthcare policies and practices.

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