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Use of Mind Body Complementary Therapies (MBCT) among Thalassemia Patients

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Abstract

This study aimed to determine the pattern use and their experiences of MBCT use in Thalassemia patients in the Northern region of Malaysia. A validated questionnaire was distributed among 390 thalassemia respondents at the Kedah Thalassemia society. Results showed that 313 (80.26%) reported using CAM. The data showed a significant association with age (p=0.001), an education level (p=0.020), and household income (p=0.037). The MBCT was mainly used among thalassemia patients, with 292 respondents (93.29%). This suggests that MBCT helps deal with stress and can be used in chronic management

Keywords: thalassemia, complementary and alternative medicine, mind-body complementary therapies, chronic

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1.0 Introduction

Mind-body complementary therapies (MBCT) such as prayers, spiritual therapies, yoga, and music therapies are reported to be used by thalassemia patients. CAM usually refers to the health care practice which is globally well-known but is not integrated with the main healthcare system (WHO, 2002). The use of complementary and alternative medicine (CAM) is increasing worldwide and is used primarily among chronic patients with illnesses including thalassemia. CAM it is commonly used among Thalassemia Malaysian population (Wan Ismahanisa Ismail et.al.,2016). CAM is recently being used frequently for chronic medical illnesses, and thalassemia is a chronic anaemia illness that usually depends on regular blood transfusion to maintain a healthy life(Bordbar et.al.,2018). Thalassemia patients also perceive that conventional medicine may cause adverse effects due to drug-drug interaction. In contrast, thalassemia patients were not provided with a proper guidelines on the use of CAM because the physicians focus on their services that are only related to conventional medicine while the patients are busy finding an alternative to treat their disease and miss out the compliance to desferrioxamine(DFO) (Wardle & Adams, 2014). Concurrent CAM and conventional methods may cause adverse effects due to drug-drug interaction and threaten their health and life (Efe et al., 2013; Wan Ismahanisa Ismail et.al.,2016). This study aimed to determine the pattern of MBCT use in Thalassemia patients.

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2.0 Materials and methods

2.1 Study design and sampling method

The quantitative phase aimed to discover the proportion of patients that gave a particular reason. The validity and the reliability of the questionnaire MBCT were checked during the pilot study, and necessary changes were made if required.MBCT questionnaire was used to find out information on the use of MBCT by people with thalassemia. This study was conducted at the Kedah Thalassemia Society in Alor Setar, Nothern region of Malaysia. All eligible participants with the inclusion criteria were approached in the four months of data collection. Each participant was identified by their identity card recorded to avoid a repeated interview with the same person. Joint ethical committees approved the study of the School of Pharmaceutical Sciences, USM, and Lam Wah Ee Hospital on Clinical Studies in Malaysia [reference: USM-HLWE/IEC/2015 (002)]. The participants comprise all ethnic groups in Malaysia, and selection was made through convenience sampling over four months.

2.2 Study instrument

There were questionnaires used as a tool for data collection. The questionnaire was used to find information on the use of CAM by people with thalassemia. A pilot study was conducted on 15 people with thalassemia to validate the suitability of the questionnaire. No changes were needed after the pilot study. The validation process required content validation. Studies were reviewed to check whether the questionnaire or instruments used could cover all the contents and were compatible with the variable used. Another validation process is face validation, which refers to experts seeking their opinion on whether the content of the questionnaire meets the requirements and needs.

2.3 Study instrument

A face-to-face interview is one of the data collection methods in quantitative research. It has a distinct advantage that allows the researcher to build a good rapport with potential participants and get their cooperation. It was conducted with the assistance of 7 members of the Kedah Thalassemia Society. There were trained to conduct interviews. Each interview session took between 10 to 15 minutes. Before each session, the principal investigator thoroughly explained the research's details and objective to the participants.

2.4 Statistical analysis

The data were managed and analyzed using Statistical Package for Social Science (SPSS) version 22. Appropriate statistical tests were used to perform descriptive and inferential data analyses. A prior significance level of 0.05 was used for all the analyses. A p-value of less than 0.05 is considered significant.

3.0 Result

A total of 390 patients were involved in this study. From 390 patients interviewed, 313 (80.26%) had used CAM for their condition. Most respondents are Malay 361 (92.56%), and nearly 357(91.54%) practice Islam as their religion. Also, most respondents have a secondary level of education 256 (65.64%).From 313 CAM used, only 292 MBCT users.

Table 1.0: Demographic Characteristic of the CAM Users and non CAM Users

Variables	CAM Users N=313 n (%)	Non CAM Users N=77 n (%)	P-value
Age Age(Mean±SD)=25.40±10.2 years			
	199 (63.7)	29 (37.6)	**0.001**
18 years – 27 years	60 (19.2)	30 (39.0)	
28 years – 37 years	41 (13.2)	14 (18.2)	
38 years – 47 years	11 (3.5)	4 (5.2)	
48 years – 57 years	2 (0.6)	-	
58 years and above			
Sex			
Male	130 (41.5)	39 (50.6)	0.148
Female	183 (58.5	38 (49.4)	
Race			
Malay	291 (93.0)	70 (90.9)	0.060
Chinese	14 (4.5)	6 (7.8)	
Others*	8 (2.6)	1 (1.3)	

Religion			
Islam	288 (92.0)	69 (89.6)	0.512
Buddhism	17 (5.4)	7 (9.1)	
Hinduism	1 (0.3)	1 (1.3)	
Christianity	3 (1.0)	-	
Others**	3 (1.0)	-	
Atheist	1 (0.3)	-	
Education Status			
Primary education	24 (7.7)	2 (2.6)	**0.020**
Secondary education	193 (61.7)	63 (81.8)	
Diploma/ Matriculation	54 (17.3)	10 (13.0)	
University degree	26 (8.3)	1 (1.3)	
Post Graduate degree	2 (0.6)	-	
Never go to school	14 (4.5)	1 (1.3)	
Others			

P value is calculated using Chi-square test
siamese, **Sikhism, ***uknown, ** odd jobs*

Table 2.0 : Types of Mind Body Complementary Therapies (MBCTs) Used by the CAM Users

MBCTs categories	MBCT Users N=292 n (%)
Meditation	23 (7.80)
Prayers	178 (61.0)
Spiritual	50 (17.1)
Tai Chi Chuan	1 (0.34)
Yoga	1 (0.34)
Others	39 (13.4)

**Reading, gardening, playing football, travelling, Art, Music, Dance*

Furthermore, MBCTs types show significant differences for β-Thalassemia major (p=0.004), duration of disease more than 5 years (p<0.001) with blood transfusion once a month (p=0.002), and significant difference recorded among respondents who received regular blood transfusion (p=0.001), iron chelation therapy (p=0.03) and supportive therapy (p=0.007). The respondents using MBCTs indicate a significant difference in CAM use with a history of conventional treatment side effects.

Table 3.0: Disease characteristics of the CAM users of different types of CAM therapies

Variables	MBCTs users N=292 n (%)
Type of thalassemia	
β-Thalassemia Major	146¥
HbE β-Thalassemia	20
α -Thalassemia	17
Thalassemia Carrier	57
Intermedia thalassemia	52
Duration of disease (Mean±SD)=3±0.82	
6 months-1 year	23
>1 years-3 years	6
>5 years	135¥
Don't Know/Not sure	128
Blood transfusion needs in a month	
Once	
Twice	200¥
More than two	14
None	4
Therapies received since thalassemia diagnosed	74
Surgery	
Regular blood transfusion	
Iron chelation therapy	132
Hormone therapy	205¥
Supportive Therapy	154¥
Do not know/Not sure	60
History of side effects due to conventional therapies	44¥
Yes	54
No	

Difficult to judge	75¥
	148
	75

¥ *P value is calculated using Chi-square test*

According to the National Center for Complementary and Integrative Health NCCIH, 2015 types were classified into five divisions: Biological based Therapies(BBTs), Mind-Body Complementary Therapies(MBCTs). Whole Medical System (WMS), Energy Medicine(EM), and Manipulative Based Therapist (BBTs).

Table 2.0 summarizes the type of MBCTs used by respondents. Among others, respondents used prayer 178 (61.0%) and a variety of other therapies, spiritual therapies 50 (17.1%) were popular among Malay respondents. There were visits to spiritual healers to get 'Holy Drink' and drink Zam Zam water, believed to cure the disease. The respondents also recite the Holy Quran as part of their therapy. The significant difference between MBCTs Cam users and non-CAM users was Malay (p=0.03).

4.0 Discussion

Most thalassemia patients use CAM, similar to the study among thalassemia patients(Efe et al., 2013). The respondents showed a significant association with CAM use among young adults aged 18-27 (63.7%) (Alwhaibi et al., 2015). The percentage of females who had used CAM was 58.5% compared to males (41.5%). Other studies attributed the higher rates of females compared to males (Alwhaibi & Sambamoorthi, 2016; Efe et al., 2013; Wendy Thompson, 2013). Females with physical and mental health problems tend to use CAM. It can cause depression among females, potentially leading them to use CAM in more than one type often, making them feel much more vulnerable to drug interaction between the conventional and CAM treatments (Alwhaibi & Sambamoorthi, 2016; Moses & McGuire, 2010). The findings confirmed that education status and monthly income were associated with CAM use. Other findings also support it because the education and finances made patients decide and explore how to treat thalassemia disease and its treatment effect(Alwhaibi &Sambamoorthi,2016).

There are significant differences in the use of CAM depending on the types of thalassemia. The respondents with β-thalassemia major (45.7%) are more users than other thalassemia types (Efe et al., 2013). This is the first study in Malaysia on CAM use related to thalassemia patients. The findings show that the Malay ethnicity is the most common user of CAM (93%) compared to other ethnicities. However, no significant difference was found between ethnicity and CAM use. This is because the majority are Malay ethnic who suffer and genetically carry the thalassemia (Thalassemia Registry, 2019). In addition, the fact that Malay ethnic groups strongly believe in traditional medicine is reflected in the findings of this study among thalassemia main ethnic groups.CAM users show side effects on conventional treatments compared to non-CAM users. More patients use CAM when their illnesses do not get better through conventional medicine. Dissatisfaction with conventional treatments causes patients to seek alternative treatments to reduce the pain of the illness they are experiencing (Astin, 1998b). It is no surprise that the current studies show education (61.7%) plays an important role in the use of CAM. Education increases the access to the information about CAM and helps choose any from the many available treatments (Alwhaibi et al., 2015)

Among CAM therapies used, most thalassemia patients use MBCTs (93.29%) as one of the thalassemia treatments. The common MBCTs used by thalassemia patients were prayer (61.0%) followed by spiritual healing (50%). This finding was hardly surprising because other studies showed the use of spirituality for health and to treat illnesses (Efe et al., 2013; Jors et al., 2015). Malaysia is a Muslim nation, and prayer is one of the practices in Islam. In other findings, prayer is used by breast cancer patients, with 95.9% perceiving that prayer can improve emotional well-being (Chui et al., 2014). Patients who practise prayer as a CAM treatment mostly have β-thalassemia major (50%). Patients with β-thalassemia major must undergo various treatments and face various side effects and symptoms. Patients with β-thalassemia major have a lower quality of life than others with mental and physical health problems (Emadi Dehaghi et al., 2016). Prayer has a positive impact on the physical and mental well-being of patients. Patients with an illness, especially a critical illness, are more inclined to perform more prayers and frequently fulfil their religious practices (Hsiao et al., 2008) to improve emotional and physical well-being.

Besides, spiritual methods are used by thalassemia patients as one coping method in wellness and are used to increase hope and improve social skills among patients. In some studies, spiritual practices are also used to help improve disease outcomes and quality of life (Cooper-Effa et al., 2001). Thalassemia patients usually have low self-esteem and are highly depressed. This is because thalassemia patients will suffer from the cradle to the grave and experience patients' physical changes (Tajvidi & Zeighmi Mohammadi, 2012). Because of the suffering and pain they experienced, they decided to continue to try and be closer to God and invoke the healing of disease both physically and psychologically. It also increases the spiritual strength of thalassemia patients to

face the disease (Anum & Dasti, 2016a; Efe et al., 2013). Spiritual wellness and prayers make the thalassemia patients feel relaxed and better. It also ensures families that every illness is curable and improves the quality of life for patients with chronic diseases (Bahrami, Balouchestani, Amini, & Eghbali, 2010a). This indicates thalassemia patients' need for psychological support. This can help patients with psychological problems because spiritual turmoil will improve their attitude towards despair, loneliness, and emptiness of life (Pouraboli, Abedi, Abbaszadeh, & Kazemi, 2014). This suggests that spirituality and religion help cope with stress and can be used in chronic disease management (Harrison et al., 2005).

In the Ministry of Health, the medical practice of Islam is recognized as one of the CAM treatments. Still, Malaysia's multi-religion and cultural practices should be respected because what is practised by each ethnicity is different.

Besides that, meditation is also one of the CAM practices, namely through recitation or devotion to God, thus establishing a divine relationship that will eventually give peace to their souls (Helminski, 2000). According to previous studies, patients with thalassemia have a higher rate of depression than any other illness (Yengil et al., 2014). Thus, this practice shows affection and love for Him by constant dhikr. Because dhikr is very easy to practice, its benefits are very unusual. Eventually, they feel at ease and are designed to any adverse destiny to test their faith. A Muslim who is constantly reciting dhikr will always gain continuous benefit as the Prophet said, "None of the people who sat (and) dhikr of Allah, but they will be surrounded by Malaika, and enveloped by the grace of Allah (who) will remember them before those who are in Him." (HR. Bukhari).

Al-Quran, in practice, is a guide for most Muslim patients. They believe and are convinced that their soul will always be calm by reading the Quran and can reduce stress. In Surah Al-Israa verse 82, Allah said, "And We send down of the Qur'an that which is healing and mercy for the believers".

And in Surah Fussilat verse 44, Allah (s.w.t) said: "Say, Al-Quran is for those who believe, a guidance and cure". The cure is in the Quran for all the diseases that come from Allah (s.w.t). It is up to the individual to discover and practice these verses and fully believe in the miracles of the Quran. Patients with thalassemia and adopting modern treatments always look for an alternative. Most of them are practising MBCTs as they are confident, believe in Allah, and are resigned to all hardships. Meditation originated in ancient religious and spiritual traditions meditation to improve pain and depression symptoms and quality of life (National Centre for Complementary and Integrative Health (NCCIH), 2015). Meditation was the fourth use of MBCT among thalassemia patients. Meditation has religious and spiritual origins and is practised because of their faith and religion. The previous study showed mindful meditation impacted physical and psychological symptoms and syndromes, including reduced anxiety, pain, depression, enhanced mood, self-esteem, and decreased stress (Hilton et al, 2017). Though many patients reported Tai Chi Chuan, it has been reported to be effective for potential effects for chronic pain conditions. Consider Tai Chi a viable complementary and alternative medicine for chronic pain conditions (Kong et al., 2016).

5.0 Conclusions & Recommendations

In conclusion, MBCT use is common among thalassemia patients. Out of 313 (80.26%) were CAM users,292 MBCTs users are the most commonly used by the respondents. This study presents useful and valuable non-medical therapy information such as prayers and meditative therapy. To promote and instil a sense of acceptance and belief in health care providers at this point that spiritual matters are significant for most thalassemia patients because they can affect behaviour and change their lives. The findings showed that many patients turn to prayer in seeking guidance about treatment and disease management decisions. CAM users believed in its effectiveness in parallel with conventional treatment, thus causing them simultaneously use both methods for thalassemia treatment. Physicians should be aware of this possibility and may find it useful in dealing with the power of prayer on patients' treatment decisions. MBCT method used by thalassemia patients is via Prayer by drawing themselves closer to God to gain peace and calm souls, hence accepting their destiny. In addition, the high use of CAM among patients with thalassemia is significant. It raises concerns about whether CAM adversely affects their health due to the reaction between the material and conventional CAM treatment methods. Since this study indicates the patient's perceived benefit from MBCT usage, thus further research should be conducted on thalassemia patients who do not use MBCT alongside those who use MBCT in determining whether or not MBCT provides benefits to thalassemia patients. The information will assist in developing educational programs for modern medical practitioners dealing with people having thalassemia. The use and disclosure of CAM use can only be understood in the larger context of life and lifelong disruption faced by thalassemia patients. It varies with another chronic disease where thalassemia patients have suffered for many years and rely on modern treatments for survival.

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Paper Contribution to Related Field of Study

Paper contribution to academic research related to Complementary and alternative medicine, conventional medicine, and also thalassemia patients.

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