RESEARCH ARTICLE

Knowledge Attitude and Practice of traditional and complementary / alternative medicines amongst End Stage Renal Disease patients in Brunei Darussalam

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Abstract

Objective: A limited study was found in regards to knowledge, attitudes, and practices (KAP) of traditional and complementary/alternative medicines (TCAM) amongst end-stage renal disease (ESRD) in South East Asian region including Brunei Darussalam. This study explored TCAM use amongst ESRD patients in Brunei Darussalam.

Methods: This was a cross-sectional study in a local Dialysis Centre using a bilingual self-structured questionnaire. Recruitment was done using systematic random sampling with certain inclusion criteria. All collected data were entered into Microsoft Excel 2016, and inferential statistics were carried out using R studio version 1.1.383.

Results: About 40.2% were TCAM users, and this was not predictable by any sociodemographic background. Nevertheless, compliance with conventional medicine (CM) was very high (94.1%). Users had a more positive disease perception, which was not affected by length on dialysis treatment or the presence of comorbidities. TCAM was perceived to be less effective and unsafe compared to CM, and patients agreed that its use should be monitored and notified. Health supplement (70.7%) was mainly used to improve general wellness (48.5%) or to relieve fatigue (42.4%), and most practices were influenced by family (43.9%). Only a minority of users (19.5%) reported side effects as majority (80.5%) consumed TCAM and CM separately.

Conclusion: High TCAM practice showed that there are still needs that are not fulfilled. The health care professionals should always remain vigilant of its use and be attentive to attend to patients' needs.

Keywords: Traditional medicine, Complementary medicine, Alternative medicine, End stage renal disease.

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Introduction

A diagnosis of chronic kidney disease (CKD) is undoubtfully difficult to accept knowing that there is no cure but only management to delay its progression. Due to this, some might have a desperate need to find a cure. In a study on attitudes of patients with CKD, Njoro reported that most patients with the disease usually seek traditional help prior to medical intervention.[1] A consequence of not having an early proper medical intervention is that the progression to end-stage renal disease (ESRD) might be advanced.

All ESRD patients require renal replacement therapy to compensate for the loss of kidney function. The therapy could be in the form of kidney transplantation or dialysis such as haemodialysis or peritoneal dialysis. Dialysis causes a lot of side effects, few of which are itchy skin, muscle cramps, bone, and joint pain, and insomnia. This results in some patients opting for complementary or alternative medicines (CAM) to improve their general wellness and avoid the adverse effects of conventional treatment.[2] Unless the patients undergo kidney transplantation, they would need to undergo at least a few dialysis sessions in a week for the rest of their lives to get rid of the toxic waste products. With unpleasant experience added to the chronicity of treatment, some might develop a negative behaviour towards conventional medicines (CM).

ESRD patients also usually have other comorbidities such as hypertension, diabetes, hypercholesterolaemia and heart disease. Such patients have multiple medications prescribed to manage their condition. This would lead to polypharmacy issues, as not taking the medicine as prescribed or stop the medication without consulting health care professional. In addition, these patients could also substitute their medication with medicines that they perceive to be capable of providing all the benefits as those in their prescription to lessen the number. Having multiple medicines for a long period has been shown to affect one's adherence to treatment.[3] Non-adherence could cause a lot of health consequences, which compromises the outcome of treatment and hence, the survival of these patients.

National Center for Complementary and Integrative Health (NCCIH) defined traditional and complementary/

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alternative medicines (TCAM) as a 'group of diverse medical and health care systems, practices and products that are not generally considered to be part of conventional medicine'.[4] Therefore, TCAM covers everything that is beyond the prescription of a medical health care professional. Most TCAM products have no content labels or appropriate certification from relevant authorities, and hence safety and efficacy could be unknown. However, it is crucial to know about TCAM information as it might have direct potential nephrotoxicity, especially to ESRD patients, due to the disturbed pharmacokinetics in the body when processing medicines.[5] Therefore, having less awareness about the consequences of its inappropriate use could be very detrimental and might risk their health or even result in death.

The information about TCAM could be attained from many resources such as books, pamphlets and mass media or informally from family and friends. Perceived safety and efficacy established from these resources might determine an individual's attitude and practice towards TCAM. Besides that, different sociodemographic backgrounds might also have an effect on their current knowledge and perception towards these medicines. For example, people who lack education might believe that traditional medicines (TM) are safe to be used due to their natural preparation however others might disagree due to their limited scientific evidence. Also, some ethnicity practices use TM for centuries. Therefore, it is likely that the practice is seen more in some ethnic background than others.

Studies done in Brunei Darussalam with regards to the use of TCAM are very limited. Only two studies were found, done in a health care setting, which reported the prevalence of TM use to be about 59%[6] while CAM about 21.1%[7] in general Brunei Darussalam population. However, amongst chronic disease patients, no study was found. Despite the small number of local studies, two figures gave a rough indication of the bulk of TCAM practice in the country. In some of the South East Asian countries, TCAM use was reported to be 95.1% in Myanmar, 27.0% in Cambodia, 26.3% in Thailand and 23.9% in Vietnam amongst patients with chronic diseases.[8,9] This shows that practice is quite common in this region amongst the chronically ill. This study explored the influencing factors (such as disease perception, compliance to CM, length on dialysis and presence of comorbidities), the prevalence and its association with certain selected sociodemographic factors (including gender, age, ethnicity, educational background, employment status and residence), and the knowledge, attitude and practice (KAP) of TCAM use.

Patients and Methods

A cross-sectional study was conducted from February 9 to March 23, 2019, at one of the largest Renal Dialysis Centre in Brunei Darussalam. A total of 111 ESRD patients on haemodialysis were included; each recruited randomly using systematic sampling from 4 cubicles apart from the previous patient. The inclusion criteria were ESRD patients aged 18 years old and above, men and women, mentally competent, able to communicate verbally, willing to participate and had complete data. The exclusion criteria were ESRD patients aged below 18 years minors, patients with communication difficulty, patients who refuse to participate and those with incomplete data.

Each patient was briefed through a participant information sheet explaining the purpose of the study, research procedure, expected duration of participation, privacy and confidentiality of data collected, risks and benefits of participation, as well as, right to refuse participation at all. Written informed consent was obtained from all the patients who agreed to participate in the study. A numbered participant code was randomly allocated on each sheet that was given to the patients to ease data analysis. The study protocol was approved by the Medical Health Research and Ethics Committee of Ministry of Health, Brunei Darussalam, and the Ethics Committee of PAPRSB Institute of Health Sciences, University Brunei.

Data collection was done by the first author in a one-to-one manner at chairside during haemodialysis sessions to improve the quality of answers from participants. A bilingual (Malay and English) self-structured questionnaire was used to aid data collection. The questionnaire was also pilot-tested using ten people with similar criteria to the targeted population before full study was conducted.

The questionnaire consisted of 5 main headings: details of patient (sociodemographic profile), medical condition, knowledge, attitudes, and practices. Knowledge was assessed using open ended questions with no answer options to prevent guessing and therefore resulting in false representation; also, to cover all possible variations in answer. Attitudes were assessed using a fixed scale (strongly disagree, disagree, neutral, agree, strongly agree) to estimate their current beliefs of TCAM. Lastly, practices were assessed using a multiple-choice answer to standardize measurements TCAM usage. There were also a few 'yes or no' questions used to determine the prevalence of TCAM use, disease perceptions and

compliance towards conventional medicine. No data that might disclose identity of the participant was collected.

All data obtained from the interview was digitalized and translated into specific codes (for example TCAM use=1 and no TCAM use=2) in Microsoft Excel 2016 for analysis purposes. Microsoft Excel 2016 was also used to carry out logical tests to determine frequencies for each question and to establish possible association between two selected responses (for example: if TCAM status = 1, show the response for perception of disease). R studio version 1.1.383 was used to carry out inferential statistics such as Chi-Square and Fisher's exact test to compare the frequency and to determine the presence of any statistically significant difference in responses for certain selected questions ($p \geq 0.05$).

Results

Out of 111 eligible ESRD patients, only 102 patients consented to be included in the study — a response rate of 91.9%. All the data collected were usable, and almost all the questionnaires were filled in by the interviewer as patients preferred to converse than to write.

Disease perceptions, compliance, length on dialysis treatment and comorbidities amongst ESRD patients are shown in Table-1. All the above factors showed no contribution (all p-value $\geq$ 0.05) to the practice of TCAM. Several common comorbidities were recorded including hypertension 90(88.2%), diabetes 58(56.9%), hypercholesterolaemia, 49 (48.0%), heart disease 23(22.5%), and gout 21(20.6%). Other medical conditions such as history of stroke or kidney stones, asthma, anaemia and calciphylaxis were also noted. Two patients specifically highlighted that they had congenital kidney disease before ESRD.

Prevalence of TCAM was high; however, there was no association with sociodemographics of users. About 41(40.2%) ESRD patients claimed to have used TCAM. The sociodemographic profile of both users and non-users were generally similar and had no significant difference (all p-value $\geq$ 0.05) (Table-2).

Knowledge: Benefits and side effects of TCAM use

The users were aware of the effects of their use. Majority (80.5%, n=33) stated to have received specific benefits from TCAM. To improve general wellness 16(48.5%), to relieve fatigue 14(42,4%) or body pain 8(24.2%) and to be able to pee 7(21.2%) were the most common benefits. Only eight (19.5%) users experienced side effects such as headache, vomiting, nausea, flu, cough, difficulty breathing, feet swelling and increased urination.

Attitudes towards TCAM use amongst ESRD patients

Perceptions were alike, but behaviour towards TCAM was different. TCAM was perceived to have equal or less effectivity and relatively unsafe, hence, necessary measures should be taken. While users were more likely to approve TCAM as part of health care, non-users showed otherwise (Table-3).

Practices: Types and modes of TCAM, details and influences of practice, reasons for use and disclosure

Practices were quite diverse and had multiple rationales. However, most users were not transparent with their

Table-1: Perception of disease, compliance, length on dialysis and comorbidities amongst ESRD patients.

		n=102	TCAM use status n (%) No TCAM n=61	p-value TCAM n=41
Possibility for cure				0.258[a]
	Yes	54	29 (47.5)	25 (61.0)
	No	48	32 (52.5)	16 (39.0)
Compliant				1.000b
	Yes	96	57 (93.4)	39 (95.1)
	No	6	4 (6.6)	2 (4.9)
Length on Dialysis Treatment (years)		0.524[a]		
	Less than 1	15	7 (11.5)	8 (19.5)
	Between 1 to 5	57	35 (57.4)	22 (53.7)
	More than 5	30	19 (31.1)	11 (26.8)
Presence of Other Medical Condition	1.000[b]			
	Yes	98	59 (96.7)	39 (95.1)
	No	4	2 (3.3)	2 (4.9)

n = number of ESRD patients; [a]Chi-squared test; [b]Fisher's exact test.

Table-2: Sociodemographic of the ESRD patients.

Variable		n=102	TCAM use status n (%)		p-value
			No TCAM n=61	TCAM n=41	
Gender	Male	48	28 (45.9)	20 (48.8)	0.934[a]
	Female	54	33 (54.1)	21 (51.2)	
Age upon data collection (years)	18 to 30	9	7 (11.5)	2 (4.9)	
	31 to 45	18	9 (14.8)	9 (22.0)	0.447[a]
	46 to 60	42	27 (44.3)	15 (36.6)	
	61 and above	33	18 (29.5)	15 (36.6)	
Ethnicity	Malay	101	60 (98.4)	41 (100.0)	1.000[b]
	Chinese	1	1 (1.6)	0 (0.0)	
Highest education level	None	1	1 (1.6)	0 (0.0)	
	Primary	19	10 (16.4)	9 (22.0)	0.282[b]
	Secondary	66	43 (70.5)	23 (56.1)	
	Tertiary	16	7 (11.5)	9 (22.0)	
Employment status	Employed	32	15 (26.4)	17 (41.5)	
	Unemployed / Retired	68	44 (72.1)	24 (58.5)	0.114[b]
	Student	2	2 (3.3)	0 (0.0)	
Residence	Brunei Muara	100	60 (98.4)	40 (97.6)	1.000[b]
	Tutong	2	1 (1.6)	1 (2.4)	

n = number of ESRD patients; [a]Chi-squared test; [b]Fisher's exact test.

Table-3: Attitude of ESRD patients toward TCAM.

Statement		n=102	TCAM use status n (%)		p-value
			No TCAM n=61	TCAM n=41	
TCAM more effective than CM					0.447[a]
	Strongly Disagree	13	11 (18.0)	2 (4.9)	
	Disagree	38	25 (41.0)	13 (31.7)	
	Neutral	34	23 (37.7)	11 (26.8)	
	Agree	8	1 (1.6)	7 (17.1)	
	Strongly Agree	9	1 (1.6)	8 (19.5)	
TCAM safer than CM					*0.006[b]
	Strongly Disagree	15	11 (18.0)	4 (9.8)	
	Disagree	47	33 (54.1)	14 (34.1)	
	Neutral	22	10 (16.4)	12 (29.3)	
	Agree	11	5 (8.2)	6 (14.6)	
	Strongly Agree	7	2 (3.3)	5 (12.2)	
TCAM should be integrated into the country's health care system					*<0.001[b]
	Strongly Disagree	6	4 (6.6)	2 (4.9)	
	Disagree	35	30 (49.2)	5 (12.2)	
	Neutral	17	10 (16.4)	7 (17.1)	
	Agree	33	13 (21.3)	20 (48.8)	
	Strongly Agree	11	4 (6.6)	7 (17.1)	
TCAM use should be under observation of a health care professional					0.086[b]
	Strongly Disagree	4	0 (0.0)	4 (9.8)	
	Disagree	18	11 (18.0)	7 (17.1)	
	Neutral	6	4 (6.6)	2 (4.9)	
	Agree	48	27 (44.3)	21 (51.2)	
	Strongly Agree	26	19 (31.1)	7 (17.1)	
TCAM use should be disclosed to the doctor					*0.003[b]
	Strongly Disagree	4	1 (1.6)	3 (7.3)	
	Disagree	19	5 (8.2)	14 (34.1)	
	Neutral	6	4 (6.6)	2 (4.9)	
	Agree	47	31 (50.8)	16 (39.0)	
	Strongly Agree	26	20 (32.8)	6 (14.6)	

n = number of ESRD patients; [a]Chi-squared test; [b]Fisher's exact test; *statistically significant at $P \leq 0.05$.

doctor. Few of the types used were health supplement 29(70.7%), physical therapy 22(53.7%), traditional remedy 18(43.9%), spiritual therapy 10(24.4%) and local therapy 8(19.5%). Most frequent reported modes were by swallowing 23(56.1%), drinking 17(41.5%) or external application 17(41.5%). Modalities such as cupping or massage 7(17.1%) and bath 6(14.6%) were also noted.

More practices started after diagnosis of renal disease 24(58.5%) and over half 23(56.1%) were attributed to other medical conditions. In addition, majority have practiced TCAM beyond 12 months 27(65.9%), used TCAM only when needed 21(51.2%) and exclusively from CM 33(80.5%), and willing to spend above BND 10 monthly 31(75.6%). Family 18(43.9%) and friends 15(36.9%) were the main influences of TCAM practices.

Effectiveness of TCAM 34(82.9%) was one of the main reasons for practice, followed by accessibility 28(68.3%), just wanting to try 19(46.3%), cultural belief 16(39.0%), religious belief 13(31.7%) and affordability 10(24.4%). Only a minority 3(7.3%) of TCAM users disclosed their use to the doctor. Reasons for non-disclosure were either due to not enquired 26(68.4%) or fear of disapproval from the doctor 25(65.8%).

Discussion

About two-fifths of the ESRD patients were using TCAM, though the contributing factors were unclear, and there were no links to their sociodemographic backgrounds. Due to having minor conditions, these patients started self-medicating using TCAM without the doctor's notice and managed to relieve some of their symptoms. Although most of the practices were very carefully used and only a minority experienced side effects, it is quite worrisome that only three users disclosed their use to the doctor.

All of the factors explored in this study did not contribute to the practice of TCAM amongst these patients. Although disease perception did not affect the status of TCAM use, users were more likely to believe in cure, whereas non-users were more likely to believe otherwise. This finding implies that a more optimistic outlook of the disease tends to result in resorting to other alternatives and hence the practice of TCAM and their positive response to incorporating TCAM into their healthcare. The positive association between disease perception and patients' behaviour has also been seen in studies of other illnesses. Firstly, in a study of patients with eating disorders, more motivation is seen in those who believed that the treatment could help in recovery.[10] Secondly, in another study of patients after an acute myocardial infarction, attendance to rehabilitation is higher in those who believe in the possibility of recovery.[11] Hence, role of health care professionals is crucial to instill a positive mindset and enhance a better health outcome.

Despite the differences in perception, almost every patient (94.1%) was compliant with conventional treatment. Compliance was surprisingly not affected by the duration of treatment, which was not the case in other studies. Chronic illnesses have been reported to be associated with high rates of non-compliance,[12-14] and in fact, World Health Organization stated that 'adherence among patients suffering from chronic diseases averages only 50%' across many studies in developing countries.[15] High compliance in this study was likely due to provision of free health care services in the country. These patients did not face any financial hardship and therefore have easy access to medications and dialysis. Besides that, it portrayed a good level of awareness amongst these patients; they understood the nature of ESRD and recognized the importance of adhering to treatment. Otherwise, this level of commitment would not be seen despite free access.

Comorbidities present in this group were mostly cardiovascular in origin with hypertension being the most prevalent. This was expected as uncontrolled hypertension has been known globally to result in kidney failure. The finding is also in line with local documentation of ESRD in Brunei Darussalam[16] and several other studies that documented aetiologies of ESRD.[17-19] Other comorbidities such as heart disease, hypercholesterolaemia, and stroke were also consistent with the findings documented for South East Asia.[20]

About 40.2% of ESRD patients have used TCAM in the past 12 months with no association at all between TCAM use status and selected sociodemographic characteristics. Although there have been studies that documented no association in majority of the sociodemographic group,[4,21] none was found where TCAM usage did not differ at all. On the other hand, others documented significant association between TCAM use and certain sociodemographic especially age, educational level and employment status.[22,23] The high prevalence could be explained by their easy access to dialysis treatment, which in turn causes side effects and, therefore, it continuously needed to be addressed.

In ESRD, patients either have decreased urine output (oliguria) or no urine output at all (anuria) due to the loss of filtering function of kidneys. Due to this, to be able to pass urine is seen almost like a privilege amongst the users. Especially in chronic illness, Charmaz stated that

'loss of self is a fundamental form of suffering'[24] and this results from various changes that happen in their bodies both physically and psychologically. Therefore, for this particular benefit, it is thought that these patients used TCAM to restore the sense of 'normal' rather than due to their poor awareness about ESRD.

Majority of TCAM was consumed when needed and separately from CM. This meticulous practice implies that users were aware of the possibility of adverse effects or drug interactions. Besides, TCAM was also not perceived to be more superior to CM and not merely used to cure ESRD but to treat minor problems. Some had started before diagnosis and patients were sure of its effectiveness implying that TCAM was already something familiar to them. Family being the main influence of TCAM was expected from this study because the care of patient in Brunei usually has a huge family involvement (family-centered). Also, it is common for an individual to share about their illness to the family, which might lead to suggestion of trying TCAM in hope to make their loved ones better.

Limitations

Although this study was conducted at the largest Dialysis Centre, it did not cover population from 3 other Dialysis Centers in the country. Hence, findings could not be generalized to all ESRD patients in Brunei Darussalam. Also, the sample only included patients that agreed to renal replacement therapy and not those who refused treatment, which might practice TCAM more than those in the sample. Furthermore, there was a high proportion of patients with a Malay ethnic background, which is not representative of whole ethnic groups in Brunei Darussalam. The responses from patients might be subjected to recall bias especially for details of TCAM use such as types, duration, frequency, and expenditure.

Conclusion

Despite the limitations, this study provided a better understanding to address high prevalence of TCAM use amongst these patients. Although users were quite knowledgeable about TCAM, its toxicity towards other comorbidities is still unknown. It is also hoped that this study provides a helpful insight into cultural behaviour towards TCAM in Brunei Darussalam especially for health care providers.

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