

Health Beliefs on Chronic Disease Management and Changes in Daily Routine among Thai Pilgrims during the Haj: A Qualitative Study

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ABSTRACT

Introduction: Serious illnesses and fatalities occur among Haj pilgrims each year, and chronic diseases appear to be the most common causes. However, there appears to be a lack of in-depth information on lifestyle adaptation and behavioural determinants of Haj pilgrims regarding management of chronic diseases during the pilgrimage.

Aim: To describe health beliefs regarding management of chronic conditions and adaptation in daily routines among Thai Haj pilgrims who had chronic diseases.

Materials and Methods: In this qualitative study, 19 pilgrims and one guide (in Mecca and Medina) were selected by purposive sampling and invited to participate in in-depth interviews after they finished the Haj rituals. Patients 18 years or above being able to communicate in either Thai or Malay languages and history of diagnosis with at least one non-communicable

disease were included. Interview recordings were transcribed by a trained transcription writer. The transcriptions were analysed using content analysis.

Results: Study participants deemed that they were susceptible to chronic diseases, and symptoms could become severe. However, participants regarded maintenance of good health as a way to follow religious principles, and the Haj was to be performed without assistance from others, when feasible. Participants also reported adapting daily routines according to medical and physical limitations, and strict adherence to prescribed medications.

Conclusion: The findings offered insights on health beliefs among Haj pilgrims as reported during the pilgrimage. However, the investigators adapted the interview questions according to the flow of the conversation, which did not allow for standardisation of the questions and responses.

Keywords: Health behaviour, Health belief model, Islam, Qualitative research

INTRODUCTION

The Haj pilgrimage is one of the five pillars of Islam that is required of all Muslims who are capable of embarking on the journey to Mecca. Religious rites during the Haj are more physically demanding than others, involving walking long distances outdoors in the desert environment in close proximity to a large number of other pilgrims. Haj pilgrims are generally older and are at risk of cardiovascular attack, electrolyte imbalance, hypoglycaemia, hyperglycaemia, and respiratory infections [1,2].

There are serious illnesses and fatalities among Haj pilgrims each year. Cardiovascular diseases and other chronic conditions appear to be the most common causes [3,4]. However, studies on health behaviours and behavioural determinants of Haj pilgrims seem to be focused on infectious diseases [5-7] or includes assessment of knowledge, attitude, and practices without in-depth exploration of health beliefs and behavioural adaptations [8].

In other words, there appears to be a lack of in-depth information and insights on lifestyle adaptations and behavioural determinants of Haj pilgrims related to management of conditions during the pilgrimage among those who have a chronic disease. Such information can provide insights for health promotion and preventive care strategies for pilgrims before and during the pilgrimage. The aim of this study was to describe health beliefs regarding management of chronic conditions and adaptation in daily routines among Thai Haj pilgrims who had chronic diseases.

MATERIALS AND METHODS

This was a qualitative study conducted among Thai Haj pilgrims and one pilgrim guide during their travels in Mecca, Saudi Arabia.

The lead investigator (MT) indicated to each participant that the interview was strictly for research purpose and not a part of any medical examination or treatment procedure. Participants who

showed sign of physical or emotional distressed were to be immediately dismissed from their participation. The procedures followed in this study were in accordance with the standards the Helsinki Declaration of 1975 (2013 revision). Permission to travel to Saudi Arabia to collect data for the study was granted by Province of Songkla University (Order No. 50555/2561 dated 28 September 2018).

The original sample size for this study was 24 pilgrims and pilgrim guides (12 from the Muslim-majority Deep South provinces, 6 from relatively affluent Bangkok Metropolitan Area, and 6 from other regions). The proportion of province of origin was to reflect the proportion among Thai Haj pilgrims.

Inclusion criteria: Above the age of 18 years; able to communicate in either Thai or Malay languages and history of diagnosis with at least one non-communicable disease. The lead investigator (MT) recruited a total of 19 pilgrims and one pilgrim guide. Other individuals who met the inclusion criteria could not be contacted later during the data collection period.

Exclusion criteria: Participants who refused to allow the lead investigator to make voice recording of the interview were excluded from the study.

Study Instrument

The study instrument was a semi-structured questionnaire. The questionnaire was created in Thai language, but the interview was administered in both Thai and Malay, depending on the mother tongue of the participant. The questions were reframed by the interviewer according to the natural flow of conversation. The questionnaire consisted of three parts, as follow:

- 1) General information about the study participant: demographics, education, income, marital status, number of children.

- 2) Details of the Haj pilgrimage: name of tour operator, expenses paid for haj trip, actions taken and difficulties experienced during the preparation phase, living conditions and adjustments to the new environment during the Haj, reason for performing the Haj in the particular year of interview, what the respondents expected from the Haj, background knowledge of the Haj, self-perceived religiousness prior to performing the Haj.
- 3) Health behaviours and the Haj rituals: existing medical conditions, health behaviours after diagnosis with the conditions, perceived effect of medical conditions on ability to perform Haj rituals, perceived importance of health in making the voyage, experience of illness during the Haj, and advice for future aspiring pilgrims who may experience health problems.

Data Collection

In Thailand, the Thai Haj Medical Office, Thai Ministry of Public Health, was contacted and notified verbally and in writing by the lead investigator (MT) about the study and data collection activities in Saudi Arabia. Later, Thai pilgrim group leaders were contacted, explained about the study, and inquired about pilgrims in each group who had chronic conditions. The group leaders were informed that the interview information would be kept strictly confidential and used only for research purpose. MT then contacted the pilgrims with chronic condition at their room of accommodation, provided information about the study, and inquired about the pilgrim's interest in participation in the interview and, among those who expressed interest, the time and place of convenience for the interview was fixed. MT also visited the field hospital established by the Thai Haj Medical Office and contacted the Chief Medical Officer on duty to verbally request permission to recruit participants and conduct the study interview. The medical officer and staff then prepared a room for interview of outpatients and recruited outpatients by convenience sampling on MT's behalf. The medical officer also allowed MT to contact inpatients at the field hospital to recruit additional participants.

In both the hotel and field hospital settings, MT explained the study procedures in details. MT also asked for the potential participant's permission to make voice recording of the interview, and that MT would place the recorder in front of the participants. MT was the only person who conducted the interviews, and obtained all informed consent verbally prior to conducting each interview. MT also ensured that the interview setting provided adequate privacy and confidentiality, and that no other person in addition to MT could hear the responses. Each interview took approximately 30 minutes to one hour.

Furthermore, before departing for Saudi Arabia, Thai Haj pilgrims were required to undergo two vaccination visits with medical examinations by local government physicians assigned by the Thai Ministry of Public Health. The examinations included interviews regarding medical history, physical examination, X-ray, and fasting blood glucose test. Based on the results of the medical examinations, the pilgrims were categorised into categories or "codes" regarding risk of health problems during the pilgrimage. There were three codes: Normal or "Green" (no elevated risk of health problems); Caution or "Yellow" (elevated risk of health problems, monitoring required), and; Dangerous or "Red" (significantly elevated risk of health problems) [9]. All groups were allowed to travel, although the code designations helped Thai health officials who worked with the pilgrims to be aware of the pilgrims' health status predeparture. Provincial Public Health Office staff then recorded the pilgrim's medical conditions and code on the Haj Handbook, which each pilgrim was required to carry during the pilgrimage. During the interview in Saudi Arabia, MT asked for the participants' permission to see their Haj handbook and recorded information regarding their medical condition and health status code verbatim.

Data Management and Analyses

MT saved the voice recording files in an offline harddisk space in a password-protected personal computer. MT then hired a trained transcription writer who was fluent in both Thai and Malay to transcribe the interviews, on condition of confidentiality regarding the names and details of the study participants. Interviews conducted in Thai were transcribed into Thai, and interviews conducted in Malay were interpreted and transcribed into Thai. MT and the transcription writer then replaced all names of the participants with pseudonyms, and used only the pseudonyms in the study reports and all subsequent publications.

MT and co-investigators (CC and WW) analysed the transcription texts. With regard to health beliefs on management of chronic diseases during the Haj, the investigators used content analysis with the health belief model [10] as the theoretical framework. With regard to changes and adaptations in daily routines during the Haj, MT and WW used content analysis.

STATISTICAL ANALYSIS

Descriptive statistics were used and transcription texts were analysed using content analysis.

RESULTS

Among the 20 participants, 16 were above the age of 60. There was a wide variety in level of education with slight over representation of participants from the Deep South provinces and under representation of participants from regions other than the Deep South and the Bangkok Metropolitan area [Table/Fig-1]. Diabetes, hypertension and lipidemia were the most common chronic conditions.

With regard to health beliefs, participants expressed concerns about occurrence or recurrence of illness but accepted illness as being unavoidable [Table/Fig-2]. Participants also understood the consequence of not managing chronic conditions and the possibility of serious complications and death, although they regarded maintaining good health as following religious principles. Having a state of health that is adequately well to perform the pilgrimage according to assessment by physicians, however, was seen as God's will and that the pilgrim should not be stubborn and act against medical advice. Participants perceived the Haj as a service ritual that requires good health, and that it is desirable to perform the Haj without the assistance from others, when possible. One participant identified the rush to perform all rites in a hurry as a potential barrier to maintain a proper state of health and safety.

The pilgrims adapted their daily routine according to their own medical and physical limitations, such as choosing to go to pray at the Al-Haram Mosque only when it is physically convenient to do so [Table/Fig-3]. Pilgrims also indicated a strong sense of medication adherence and care-seeking behaviour when experiencing illnesses. The extent and method of self-care varied, but dietary compliance for diabetes control seemed to be the most commonly mentioned issue of concern.

DISCUSSION

This study described health belief of Thai Haj pilgrims with regard to management of chronic diseases and adaptations in their daily routine. Although the pilgrims strived to maintain their health to complete the pilgrimage and return home safely, they also perceived their susceptibility and the severity of potential complications of chronic diseases during the pilgrimage. Participants seemed to adapt their daily routine to meet this aim, with awareness of the need for medication compliance.

Spirituality emerged as one of the main themes in health beliefs pertaining to chronic diseases among our participants. Spirituality can be an important resource for coping for Muslim patients who are confronted with chronic diseases [11], and the pilgrimage may

Region of origin	Sex	Age (years)	Education	Chronic conditions*	Code*
Deep South provinces**	Male	63	4 th Grade	Diabetes, hypertension, gout, kidney failure	Dangerous
Bangkok Metropolitan area	Male	66	Bachelor's degree	Obesity, pressure sores	Dangerous
Bangkok Metropolitan area	Male	39	9 th Grade	Cardiovascular disease	Normal
Other regions	Female	66	Associate's degree	Diabetes, lipidemia	Caution
Deep South provinces	Male	38	Master's degree	Post-dengue hemorrhagic shock with multiorgan failure (contacted dengue 3-4 years prior to Haj according to interview)	Dangerous
Deep South provinces	Male	67	10 th Grade	Gout	Caution
Other regions	Female	54	4 th Grade	Diabetes, Lipidemia, Hypertension	Normal
Deep South provinces	Female	57	4 th Grade	Diabetes, Lipidemia, Hypertension	Normal
Deep South provinces	Male	86	None	Hypertension	Normal
Deep South provinces	Female	75	None	Diabetes	Normal
Deep South provinces	Male	60	6 th Grade	Diabetes, Lipidemia, Heart Disease, Herniated Disc	Normal
Deep South provinces	Female	65	None	Diabetes	Normal
Deep South provinces	Male	63	Bachelor's degree	Enlarged prostate	Caution
Bangkok Metropolitan area	Male	82	None	Hypertension	Normal
Other regions	Male	61	None	COPD, Asthma	Normal
Bangkok Metropolitan area	Male	62	High school	Diabetes, Hypertension, Lipidemia	Normal
Bangkok Metropolitan area	Male	62	9 th Grade	Lipidemia, Hypertension, Chronic Pneumonitis	Normal
Deep South provinces	Male	60	Doctoral degree	Diabetes	Normal
Deep South provinces	Male	69	High school	Diabetes, Lipidemia, Hypertension	Normal
Deep South provinces	Male	60	Master's degree	Lipidemia	Caution

[Table/Fig-1]: General characteristics of the participants.

*Medical conditions and health status of the pilgrim as written in the Haj Handbook issued by the Thai Ministry of Public Health after predeparture medical examinations, unless otherwise noted; **The participant was a pilgrim guide at the time of study.

Domain	Theme	Modified expression
1) Perceived Susceptibility	1.1) Concerns about occurrence or recurrence of illness	<p>"(Medical conditions) are not an obstacle for me, but I get scared (sometimes). At first I had stomachache pain and could not pass stool.... I perform (the Tawaf - circumambulation of the Kaaba) a few times per day... I had some fatigue, but I was not exhausted"</p> <p>- Participant 3</p> <p>"I did not think (of complications) when I got on the plane. I felt normal. I told my family that my body seemed to be improving... Things were normal during the first few days, but then the (symptoms of arrhythmia) started... I felt as though I was going to faint." - Participant 4</p> <p>"I was quite worried (about my gout). I was scared of not being able to walk properly"</p> <p>- Participant 6</p>
	1.2) Acceptance of illness as being unavoidable	<p>"I developed kidney disease after arriving here... My heart was normal when I got on the plane at Hat Yai Airport, but once I arrived in Medina I had to use the wheelchair... I had knee pain.... I could only take small steps. Everything was wrong with my tendons... Obviously, I am worried because I have always been sick... But I figured that there was not much I could do. People get sick."</p> <p>- Participant 9</p> <p>"I'm not scared (of serious illness or death)... (If I get sick or seriously ill) I would look at it as a test from Allah. Allah allowed me to come. My heart has been commanded"</p> <p>- Participant 7</p>
2) Perceived severity of chronic diseases	2.1) Perceived possibility of death amidst intention for health maintenance	<p>"It's worse here. My asthma was not this bad back home (I insist that the Dua has been answered) because of Allah's taqdir (agency). I performed all Rukn (tasks) and I got sick in the end, after finishing the Tawaf and I was about to go home ... (If I was to die here in Mecca) I will have no regret. We are all heading to that final place.... Tawakkul (trusting in God's plan). Whatever will be, will be."</p> <p>- Participant 15</p> <p>"I'm worried about getting sick, but I am not worried about going on the Haj. I'm worried whether I would get better, whether I would be cured. I wondered whether it would be fatal ... Inshallah, it's all the will of Allah. It's up to Him, not me. But I say dua that I will live a long life and that nothing happens yet. I pray to get home safely."</p> <p>- Participant 4</p> <p>"After arriving, I made a dua to God for a healthy body ... I took my medications regularly... I have always taken care of my health. I also say dua to Allah ... If anything is to happen, it is up to God ... but deep down, I don't want anything to happen... My niat (intention) is to journey back and live safely."</p> <p>- Participant 8</p> <p>"I'm not afraid [of dying]. Whether at home or elsewhere, when it's my time to go, then I go... But I still keep trying [to take care of my health]." - Participant 1</p>
	2.2) Perceived consequence of not managing chronic conditions	<p>"... As for the lipidemia, if I don't control it ... I will feel faint when I walk long distances. Um, I think it's important, but if I keep connecting the Haj to illnesses, that wouldn't be the right thing. Medications can only alleviate symptoms, but what will cure us is Allah (SWT)"</p> <p>- Participant 5</p> <p>"... I am scared of getting to the point that I cannot complete the Haj. I have travelled all the way here and I want to do everything myself. I don't want to hire the help of others to do things for me."</p> <p>- Participant 6</p>
3) Perceived benefits of managing chronic diseases	3.1) Following the scriptures (in addition to completing the pilgrimage)	<p>"In Islamic teaching, there was a quote regarding health and Haj: "Those with good health are better than those with poor health". This is also mentioned in other places Pilgrims who come to perform the Haj in poor health ... will struggle."</p> <p>- Participant 13</p>

4) Perceived barriers	4.1) The need to rush through activities	"Once we are here, everything is in a rush. One needs to be quick. It's rather difficult to care for those in relatively poor health (during rituals). One needs to move quickly when performing Haj rituals...such as at the Plain of Arafah. Pilgrims can only stay there for half a day... That is the time when one truly needs to move quickly...You need to go there in groups. People will herd you in...This is the most frightening part where unpredictable things can happen." - Participant 13 "The Plain of Arafah [was the most physically challenging ritual]. It was hard for me to keep up with others" - Participant 19
	4.2) Buffet food provided by the hotel	"(The food) here is like a buffet. It looks like Thai food...Those with good appetite gain weight. But I couldn't eat much. I didn't have the appetite." - Participant 8
5) Cues to action	5.1) Medical care provided by the pilgrimage travel operators	"I have had two injections for pneumonitis... It was not too hard. I take care of myself according to the doctor's orders...The company made arrangements for doctors to be here." - Participant 17
6) Health motivation	6.1) Perception of the Haj as an Ibadah (service) that requires good health	"Performing the Haj is an Ibadah (service) that requires strength. It's not like the prayers or giving alms... I say extra prayers when I'm on the Haj...because I know my own health. I am always assessing myself." - Participant 15
	6.2) The desire to independently perform rituals (potentially driven by social norms to not be over-reliant on others)	"If I'm on a wheelchair and someone needs to serve me, I don't want to bother them too much...I wouldn't feel comfortable if I bother other people too much and they feel annoyed." - Participant 18 "I have to rely on myself first. I need to walk around and do other things once I am here ..." - Participant 2
	6.3) Enabling state of health (or otherwise) being part of God's Will	"Before I came here, the doctor had to check whether I was physically well enough...If we were in the Red group, the doctors would warn that they could not guarantee our safety...We think of getting the Red code as not being in the time that Allah wills us to make the Haj. Allah had not yet called us to perform the Haj." - Participant 20

[Table/Fig-2]: Health beliefs regarding management of chronic diseases among Thai pilgrims during the Haj.

Changes and adaptation	Response
1) Adaptation to barriers posed by chronic conditions or weather	"I did not go (to pray at the Al-Haram Mosque) because I was sick ... (I went there) to pray the Salat al-maghrib and Salat al-isha...I did not go at other times because the weather was very hot. Tour Leader told us to save our strength for the Haj." - Participant 8 "There were times when I could not perform (the Ibadat) completely because I was tired...On days that I felt strong, I would go for the Salat al-zuhr, but in the day time, I would pray at my accommodation." - Participant 10 "At the end, I may have to hire others to perform the rite. In my religion, Allah has Hukm (judgement) that provides a solution...If we cannot do things ourselves, we find substitutes. There are always solutions ... I did not go (to pray at the Al-Haram Mosque)...I try to care for myself and pray at a mosque near the hotel." - Participant 15 "[In Mecca] I only went to the Al-Haram Mosque a few times. It was hard for me to walk long distances. There was a lot of pain. I only went to the grand mosque once in a while, such as on Fridays..." - Participant 11
2) Sleeping problem	"Sometimes I could sleep. Other times, I couldn't... Lately I've been coughing. I cough when I wake up. I also urinate often. I have to wake up to urinate." - Participant 2
3) Care-seeking behaviour for Gout while performing pilgrimage	"...(I've done) the Tawaf seven times...It was only on this morning that I felt a slight ache. There was pain from gout. So I went to see the doctor because I was afraid that my conditions or the pain would get worse." - Participant 6
4) High level of self-reported adherence to prescriptions (filled before departure to Saudi Arabia)	"I've always taken my medication. My doctor gave me advanced prescription for the days that I would be here." - Participant 8 "I take medications as the doctor ordered. Nothing special ... I feel fine after arriving here." - Participant 10 "I prepared medications. When I was in the mina (encampment), the weather was hot. I just kept taking my medications." - Participant 16
5) Health behaviours/ Self-care	"It's only food that I had to control. Other things went on as normal. There was no extra care needed." - Participant 8 "(on health) I am more careful than usual...Being careful refers to my eating habit ... Because I don't want to feel tired." - Participant 12 "Those with diabetes tended to be too disciplined with regard to food... There are enough doctors around to take care of us here, but they still would not eat. As a result of this over-caution, their blood sugar dropped and they felt fatigue, numb, and could not walk." - Participant 13 "The food is decent. It's similar to what we have back home. There's a buffet. But I cannot eat much. It's not too good. I want something different." - Participant 14 "If I started feeling unwell, I would take some candy or electrolyte solution...I brought electrolyte powder because there's quite a bit of glucose there. I also bought some candy: coffee flavour, plum flavour. When I felt that I was losing balance, I would take a few pieces and feel more refreshed." - Participant 18 "I got some water from the Zamzam Well to drink so that Allah would open up His heart and help me to have a stronger body. But it did not help and my conditions worsened." - Participant 9

[Table/Fig-3]: Changes and adaptations in daily routines among Thai Haj pilgrims with chronic diseases during the Haj.

have heightened this sense of spirituality. The acceptance of poor health as a sign that God had not allowed for the pilgrim to make the journey, as well as the acceptance of the possibility of serious illness

or death while on the pilgrimage, could be influenced by the belief in qadar or God's predestination [12] and is used as a psychological defense mechanism. The desire to maintain good health, on the

other hand, may reflect the influences of various Quranic verses and traditions [13]. The findings of the study has implications on the key role that spirituality can play an important role in health promotion. Achieving good health and management of chronic diseases can be considered as a mean to embark on the pilgrimage and successfully complete the Haj, which includes physically demanding rituals in the holy land. Furthermore, in consideration of the prevalence of chronic diseases in the elderly population and that most pilgrims are elderly persons with varied backgrounds [3,4], future studies should explore the extent that the patients were educated and advised by healthcare providers and pilgrimage operators about management of their chronic conditions during Haj-specific rituals, and adherence to these advices [5]. The strength of the study was that the data were collected during the pilgrimage, thus reducing the possibility of recall-associated errors.

Limitation(s)

A number of weaknesses should be considered as caveats in the interpretation of the study findings. Firstly, the use of semi-structured questionnaires and adaptation of interview questions according to the flow of the conversation precluded standardisation of the questions and responses. Secondly, inaccuracies in translation of Malay-language interview recordings into Thai-language transcripts could have introduced errors to the study data. Lastly, data were collected only from pilgrims from Thailand, which limited the study's generalisability.

CONCLUSION(S)

In-depth interview of Thai Haj pilgrims showed perceived susceptibility and severity of chronic disease complications, but also a sense of spirituality and adaptation of daily routine to cope with physical limitations. Pilgrims also appeared to have high level of medication

adherence during the Haj. The results complement the findings of previous studies, although a number of caveats and limitations should also be considered.

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