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Barriers to and Facilitators of Asthma Care For Malaysian Hajj Pilgrims

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Barriers to and facilitators of asthma care for Malaysian hajj pilgrims: a qualitative study

ABSTRACT

Asthma exacerbations are among the commonest reasons for hospitalisations in Malaysian pilgrims during the Hajj. We interviewed twenty-one stakeholders involved in the pre-Hajj health examination at 14 primary care clinics, to explore their perceptions on barriers to and facilitators of asthma care for Hajj pilgrims. The disadvantages of the short timeframe and centralised organisation of the pre-Hajj health examinations were viewed as compromising clinicians' level of competencies in asthma care, which could potentially be enhanced through more training, audit and supervision by specialists. Longer time frame to permit sufficient disease control, provision of care by a dedicated asthma team, asthma registry to support continuous care, more resources of long-acting β -agonist/inhaled corticosteroid and provision of influenza and pneumococcal vaccines at no cost were the perceived facilitators. Delivery of asthma education especially the asthma action plan should be tailored to the level of the pilgrim's health literacy and facilitated by educational resources, family engagement and regular health briefing.

Keywords: asthma, Hajj, primary care, asthma care

What we already know

- Pre-Hajj health screenings have been implemented in a number of countries including Malaysia in order to optimise pilgrims' health status to perform the pilgrimage.
- Gaps in asthma care exist in primary care practice.
- Limited health literacy is a barrier to the provision of asthma education which in turn affected patients' asthma self-management.

What this article adds

- The current system of Hajj fitness certification compounded the health care provider's knowledge and competency in asthma care.
- Gaps in primary care practice including shortage of resources could adversely affect the quality of asthma care provided to the Hajj pilgrims in Malaysia.
- Delivery of asthma education to Hajj pilgrims should be tailored to the level of literacy and facilitated by educational resources, involvement of pilgrim's family member, and regular health briefings.

INTRODUCTION

It is obligatory for all Muslims who are financially and physically able to perform the Hajj at least once in their lifetime¹. More than two million people from over 140 countries undertake the Hajj every year². Hajj 2019 started on August 9 and ended on August 14. During Hajj, the crowding, extreme environmental factors, intense physical activities and mental stress heighten health risks, with respiratory system ailments being the most common problem^{3,4}. Asthma is among the top causes of hospitalisation and unscheduled medical attendance during the Hajj due to acute exacerbations and its complications^{5,6}. It has been associated with pneumonia^{5,6}, and severe sepsis⁷. About one in eight (13%) of the Malaysian pilgrims who were hospitalised for pneumonia during Hajj 2012/2013 had asthma⁷.

Before COVID-19 restrictions, approximately 30,000 Malaysian pilgrims perform the Hajj every year⁸ of whom a substantial number are elders and infirm. It is mandatory for all pilgrims to be certified as physically fit for the pilgrimage⁹. Pilgrims with chronic disease, are encouraged to undergo a preliminary assessment prior to the official Hajj health examination preferably with their regular doctor or clinic. Pilgrims who are deemed unfit are referred for further evaluation. The time frame for the entire process of Hajj fitness certification is between 3-4 months from issuance of the Hajj offer letter to departure for pilgrimage¹⁰. The Hajj Fund Board (HFB) is the key institution that provides facilities for the welfare of Malaysian Hajj pilgrims while the Ministry of Health (MOH) supports various aspects of pilgrim's healthcare in the homeland and during the pilgrimage.

Given the extensive health risks posed by asthma during the Hajj, optimising asthma control and equipping pilgrims with adequate asthma education and self-management skills is a priority. We aimed to explore the perceptions of various stakeholders engaged with the Hajj health examinations on the barriers and facilitators to optimising care for pilgrims with asthma and the potential interventions to improve care.

METHODOLOGY

We purposely recruited stakeholders from 12 public and two private primary care clinics involved in providing Hajj examinations in 2019. Two clinics were selected from each region of North, South, East, and West of Peninsular Malaysia, and Sabah and Sarawak in East Malaysia. These clinics were selected to offer diverse organisational arrangements including the location (urban and rural), infrastructure and facilities (larger and smaller clinics) and the estimated number of pilgrims in the district to reflect a range of workloads. Potential participants included medical officers (MO) and family medicine specialists (FMS) from public and private primary care clinics, policymakers from MOH and HFB managers who were approached to participate in the study two weeks prior to the Hajj health examination day via telephone, text messages or email. Medical officers are non-specialist doctors who serve public hospitals or clinics while general practitioners are non-specialist doctors who practise in private clinics. FMS is a qualified specialist in family medicine. The HFB manager represented the health service of Hajj management. All participants were given written information about the study and those who agreed to participate signed an informed consent form. In-depth interviews were conducted by six academic primary care physicians in Malay or English and guided by a semi-structured topic guide (*see supplementary material*) which was developed based on a health belief model conceptual framework¹¹. This framework was constructed based on existing theoretical evidence in the literature and the researcher's experiential knowledge and opinion. Interviews at the 14 investigation sites were conducted between March 16 to March 31, 2019. Interviews were held in private rooms in the clinic to ensure confidentiality and allow interviewees to speak freely and lasted between 32-53 minutes. Interviews were conducted until data saturation was reached i.e., when no new themes emerged. After each interview, the researchers reflected and made notes to help identify personal biases and experiences that might have influenced the interviews and data interpretation. All interviews were audio-recorded, transcribed verbatim in the original languages, checked independently for accuracy and de-identified before analysis. Data were managed using NVivo 12 software. Thematic analysis was employed through constant comparison to identify recurrent themes based on the research objectives. The interview transcripts were read repeatedly for familiarisation and the texts were coded line-by-line independently by two researchers, AIAB and LSM. Any coding discrepancies were resolved through consensus. A written and graphical summary of the issues was created for each code using the one sheet of paper (OSOP) method where every section of data relevant to that code from all the interviews was noted. New themes that emerged were added to the list in discussion amongst researchers, and associations were identified to form larger concepts. Data analysis was iterative, discussed with the multidisciplinary research team, and ongoing throughout the study as new insights emerged from the data. To enhance the validity and reliability of the findings presented, the results were shared with several participants who commented the data as accurate and the themes created as adequately reflected their real experience. Through reflexivity, researchers examined the influence of their own beliefs and judgment upon the analysis. Frequent discussions and revisiting the analysis among the research team helped to assure the quality and trustworthiness of the results. Quotes used in papers and reports were translated into English.

This study received permission from the State Health Department directors and ethics approval from the National Medical Research Register - Medical Research and Ethics Committee (NMRR-MREC) (NMRR-18-2997-43555), from the MOH and from the sponsor: Academic and Clinical Central Office for Research and Development (ACCORD) ethics committee, United Kingdom.

Results

Table 1 outlines the demographic data of the participants.

Table 1 Demographic information of study participants (n=21)

Demographic information		Number
Sex	Male	7
	Female	14
Age (years)	21 -30	1
	31 - 40	11
	41 - 50	7
	> 50	2
Position	Medical officer	9
	Family medicine specialist	8
	General practitioner	1
	Ministry higher officer	1
	Health service manager	2
Work place	Public primary care clinic	17
	Private general practitioner clinic	1
	Ministry of Health	1
	Hajj Fund Board	2
Total working experience (years)	< 10	7
	10 - 20	10
	> 20	4
Experience with Hajj health examination (years)	< 5	12
	5 - 10	8
	> 10	1

Themes were related to organisational, primary care practice and pilgrims' considerations and summarised in Table 2.

Table 2 Themes and subthemes of results

Themes	Subthemes	
	Barriers	Facilitators
1. Current system of Hajj fitness certification	<ol style="list-style-type: none"> 1. Short time frame of Hajj fitness certification 2. Disadvantages of centralised Hajj health examination 	<ol style="list-style-type: none"> 1. Longer time frame of not less than 6 months 2. Preliminary health screening before Hajj health examination
2. Asthma management in primary care practice	<ol style="list-style-type: none"> 1. Poor clinical competencies of primary care doctors 2. Resource constraints 	<ol style="list-style-type: none"> 1. CME, audit and supervision by family medicine specialist 2. More ICS/LABA for uncontrolled asthma pilgrims 3. Dedicated asthma team 4. Asthma registry to support continuity of care
3. Level of health literacy	<ol style="list-style-type: none"> 1. Older pilgrims 2. Pilgrims with limited health literacy 	<ol style="list-style-type: none"> 1. Supporting asthma education resources 2. Regular health talk before and during the pilgrimage 3. Engagement of family members to facilitate delivery of asthma education

LABA, Long-acting beta agonist, ICS, inhaled corticosteroid, CME, continuous medical education

The current system of Hajj fitness certification

The 4-month time frame from the issuance of the Hajj offer letter until pilgrims left for Hajj was perceived as limiting opportunities for optimising disease control and provision of health education and participants considered 6 months as more realistic. Preliminary health screening prior to the official Hajj health examination allowed for early initiation of control measures and interventions.

‘It takes at least three months for disease stabilisation. Six months is nice because the longer period enables us to provide health advice too’. [P20, 37-year-old, male, general practitioner, 5 years of experience].

‘Our time with patients is limited, so it is impossible to educate or correct any misconceptions. Longer time is needed’. [P1, 29-year-old, male, MO, first experience].

There was variation in the organisation of Hajj health examinations among public primary care clinics. Districts that offered centralised Hajj health examinations arranged for all pilgrims from the district to undertake the examination at the same venue on fixed dates. On the examination day, time constraints due to a large number of pilgrims hindered proper clinical assessment and

provision of asthma education. The medical records of pilgrims from other clinics were not available at these designated clinics and had compromised a comprehensive clinical evaluation. An electronic asthma registry could facilitate the continuity of care after the Hajj health examination including the monitoring, and updating of the pilgrims' health status and treatment during and after the pilgrimage.

"If the asthma is uncontrolled, we have to trace the medical notes from their regular clinics. So, it is difficult because we don't have all the information here". [P18, 34-year-old, male, MO, 1 year of experience].

"HFB entered the pilgrims' data into the computerised system based on the information written in the Hajj treatment book. We can refer to the information and update the pilgrim's current status for continual care". [P6, 41-year-old, female, FMS, 8 years of experience].

Most doctors regarded the Hajj health examination as merely for certification of fitness for pilgrimage. They felt the pilgrim's regular doctor and/or clinic were responsible for disease control and optimising asthma treatment. However, one participant felt otherwise.

"We are here today only to certify them as fit or otherwise, not to manage their disease. We don't run outpatient clinics today and we don't give health advice as we do during normal follow-ups. It should be done by their regular doctors". [P19, 42-year-old, female, FMS, first experience].

Gaps in the management of asthma in primary care

A number of participants presumed some primary care doctors as not equipped with the knowledge and skills to assess and manage asthma adequately. Some were described as focusing on managing acute events, with no time given to optimisation of routine treatment. Doctors' competency in asthma care for pilgrims could be improved through the Hajj training provided for health care providers, interactive continuous medical education and regular audits and supervision by FMS.

"Medical officers did not measure peak flow and they did not step up the medications for patients who came frequently for nebuliser but only treated their acute problem each time". [P4, 39-year-old, female, MO, 2 years of experience].

"Through the Hajj training, I am aware that I must be more meticulous in my assessment. I am worried about missing a diagnosis of a serious health problem". [P10, 31-year-old, female, MO, 2 years of experience].

"We do regular audits on several cases by checking the medical officers' notes. If there is a shortfall, I will either give advice to all in general or correct the doctor individually". [P19, 42-year-old, female, FMS, first experience].

An asthma clinic with a dedicated team was viewed as able to provide comprehensive asthma management encompassing all aspects of asthma care by each member with their defined role.

“Dedicated asthma clinics with trained doctors and nurses can provide more focused management to pilgrims with asthma. The team can provide asthma education sessions, which will help to create insights of the importance of asthma.”. [P5, 37-year-old, male, MO, 7 years of experience].

There was limited availability of LABA/ICS for poorly controlled asthma where the demand exceeded the small quota available in primary care clinics. Influenza and pneumococcal vaccinations were encouraged for high-risk pilgrims (including those with asthma) but neither were available at public health facilities so pilgrims regarded this vaccination as ‘unimportant’. Pilgrims who opted to have unavailable treatments or vaccination, had to attend a private GP clinic which was unaffordable for some and thus hindered optimal asthma care.

“We can’t afford to give LABA/ICS like Seretide and Symbicort to all because the quota is small and limited. Patients could not afford to buy for longer than two to three months. Hopefully, we can buy more because indeed there are many asthma patients who require it”. [P15, 44-year-old, female, FMS, 15 years of experience].

"My feeling is, most of them [pilgrims] didn't get it (influenza and pneumococcal vaccines). They think, it is not that important since it is not provided by the government, ". [P7, 53-year-old, female, FMS, 10 years of experience].

Health literacy and awareness of asthma among pilgrims

Doctors emphasised asthma action plans, adherence to medication, correct inhaler technique and avoidance of triggers as foremost asthma education for Hajj pilgrims. Some pilgrims especially the elderly patients had difficulties understanding their disease and did not regard asthma as an important medical problem. This resulted in the incorrect use of and non-adherence to asthma medications, especially the controller. Some patients also had limited self-management skills so they did not follow their asthma action plan. Participants recognised the challenge of educating people with limited health literacy and considered that for elderly pilgrims, the presence of a family member, especially the children, would facilitate the delivery of asthma education. Supporting educational resources in printed or electronic format could be used and disseminated via social media platforms. Asthma education could be further reinforced through regular health talks by the Public Health during the pilgrimage.

“The important asthma education is how to recognise symptoms and how to act, so they don’t wait until they cannot speak to seek treatment. And also, how to use correct inhaler techniques because most of the patients’ techniques are poor”. [P14, 32-year-old, female, MO, 1 year of experience].

“For those who are educated, their acceptance of asthma education is easier. But elderly pilgrims had difficulties in understanding. The presence of family members would help”. [P11, 40-year-old, male, HFB manager of health services, 3 years of experience].

“We can give the asthma action plan through something like a leaflet containing information on the early signs of asthma attack and how to act, so they will not get worse”. [P19, 42-year-old, female, FMS, first experience].

DISCUSSION

There are major opportunities for improvement of the current organisation and implementation of Hajj fitness certification and asthma care in primary care practice. A longer time frame, enhancing the clinical competency of primary care doctors, overcoming resource shortages at public primary care clinics and accommodating pilgrims with lower health literacy were deemed as potential enablers of quality asthma care among Hajj pilgrims.

The short time frame and centralised organisation of the Hajj health examination has influenced some doctors' attitudes towards the Hajj health examination as they regarded it as a one-off patient encounter. An asthma registry was viewed as an approach to address this gap by facilitating continuity of care. There is a lack of data from other countries for comparison though many Muslim-majority countries practice routine pre-Hajj health screening¹². In Indonesia, the Hajj health screening and care is undertaken within the prospective pilgrims' waiting time, of around 20 years on average¹³. Nevertheless, despite the long window of opportunity to optimise pilgrims' health, their system was found to be inefficient in managing pilgrims' health issues.

Participants highlighted some important gaps in asthma care by primary care doctors in public health clinics including inadequate assessment of control, little treatment intensification for poorly controlled patients and no provision of asthma education. This corresponds with findings from the recent literature which underscored the challenges contributing to these three gaps^{14,15}. Effective training through accessible continuous medical education could help overcome the knowledge gap and acquisition of improved attitudes and behaviours, skills and clinical outcomes¹⁶. Training and development through sharing good practices and personal reflection are important contributors to positive attitudes among doctors¹⁷. Supervision and specialist guidance could ensure the guideline recommendations being followed by doctors upon assessment and management of pilgrims with chronic diseases including asthma¹⁷. Delivery of care by a dedicated asthma team consisting of appropriately trained personnel was shown to improve the provision of asthma action plans and medication adherence among people with asthma¹⁸. Previous studies have also highlighted the importance of interprofessional collaboration between medical officers, specialists, pharmacists, nurses and other health care providers in order to provide more accessible and personalised education and improved quality of asthma care which ultimately could reduce acute workload and time constraints¹⁹.

Tight quota-based access to medication (such as LABA/ICS) in public primary care clinics restricted treatment options for pilgrims with uncontrolled asthma. A previous study highlighted difficulties faced by patients with asthma in getting appropriate medication²⁰. Lack of financial resources for the recommended influenza and pneumococcal vaccinations amongst pilgrims with asthma was a disincentive, leaving pilgrims at risk of influenza and *Streptococcus pneumoniae* infections²¹. A new mandatory vaccination policy for Malaysian pilgrims requires sufficient data on the burden of vaccine-preventable disease during Hajj and the cost-effectiveness²² and the cost burden should be properly addressed by MOH and HFB. Primary care public-private partnership²³ and/or collaboration between MOH and HFB in the financing of resources such as the LABA/ICS inhalers and, pneumococcal and influenza vaccinations could be considered to address the resource constraint.

Most pilgrims from around the world including Malaysia are elderly with multimorbidity and at substantial risk of further morbidity and mortality, so adequate preparation including the understanding of the disease and the impact of the Hajj is essential²⁴. Pre-travel advice and educational health campaigns were found to be associated with positive health practices amongst pilgrims during Hajj^{25,26}. In Malaysia, around 60% of people with asthma were found to have limited health literacy²⁷. Adults with asthma who have limited health literacy had worse general health and functional status and significant adverse outcome, and tend to have incorrect beliefs about the disease resulting in non-adherence and/or incorrect medication use and inadequate self-management^{24,28}. Pragmatic approaches to improve asthma outcomes should be tailored to levels of health literacy in order to support learning and understanding while helping healthcare providers to deliver education within the time constraints in busy clinics. Accessible and engaging health education is the mainstay of health behaviour change and a video focusing on the desired behaviour change could be impactful²⁹. For pilgrims with lower health literacy, a combination of videos²⁹ and pamphlets using simple language and pictures to facilitate the delivery of health information could improve knowledge and comprehension. This measure can be incorporated and applied during the Hajj health examination activities and throughout the pilgrimage. A family companion could facilitate information exchange within medical encounters³⁰ in the homeland.

Using asthma as an exemplar chronic disease, policy change on the implementation of Hajj fitness certification in Malaysia by the HFB and MOH is essential to improve the care of pilgrims with presumably all non-communicable diseases. However, due to different practices between countries, our results may not generalise to other countries.

Conclusion

The current system of Hajj fitness certification and gaps in primary care adversely affect the quality of asthma care for Hajj pilgrims. It is important to address the poor health literacy among pilgrims in order to enhance the delivery of asthma education and adequate practice of asthma self-management.

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