

Original Article

A QUALITATIVE STUDY EXPLORING THE IMPACT OF STIGMA IN THE LIVES OF ADULT ASTHMA PATIENTS IN SELANGOR MALAYSIA

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ABSTRACT

Objective: This study aimed to address and explore the issue of stigmatization and its dynamics in asthma patients from hospital and community pharmacy settings.

Methods: The qualitative study approach was used to explore the issues of stigma thoroughly and deeply in asthma patients. In this study, eighteen adult asthma patients were approached for interview from two different healthcare service settings i.e. academic hospital and community pharmacy from Selangor, Malaysia. Patients' responses were recorded manually as well as electronically. The tapes were verified for accuracy of transcription. Data obtained was coded independently for the relevant themes.

Results: The majority of the interviewees were Malays i.e. 10, 55.6% and remaining 5 (27.7%) and 3 (16.7%) were Indians and Chinese respectively. The mean±SD age of the patients was 49.3 (±11.02) and among these majority were females (n=12, 66.7%). The main findings of study defined three main themes that included stigma of asthma in terms of extent of disclosure about diagnosis status; discrimination felt in the society; patients' feelings affected by stigma and different ways adapted to tackle stigma of asthma.

Conclusion: The patients' experiences of stigmatization were common in both study settings i.e. community pharmacy and hospitals. The patients' adaptation to asthma needs to be given an in-depth consideration to deal the psychosocial concerns of stigma. The support from the healthcare professionals, family members, friends and co-workers is the right strategy and way forward to improve psychosocial wellbeing of the asthma patients.

Keywords: Stigma, Adult asthma.

INTRODUCTION

Asthma has diverse psychosocial implications that affect the patients' asthma control and management of asthma [1]. According to Global Asthma Report (2014), asthma symptoms like breathlessness usually lead to the feeling of fear, emotional and psychological suffering in asthma patients. The stigma associated with diagnosis of asthma is among the major obstacles in course of better asthma management. The stigma of asthma may influence the asthma management and control by different ways. For instance, the stigma of asthma can delay health seeking services and case detection, decrease the adherence to long-term asthma management because of certain thought processes. These processes in turn hinder everyday social life of the asthma patient. In some cases people reported reluctance to marry asthma patient to avoid passing the disease on to future offspring. Furthermore, stigma is also attached with inhaler use especially in the public gatherings. The asthma patients avoid to use inhaler in public places because of this stigma attached with asthma [2].

Patients living with asthma experience more psychological problems and worse social functioning than other normal members in the community [3]. The phenomenon of stigmatization, whether had arisen by patients' feeling or as felt because of the other community members, had a series of negative consequences to the asthma patients [4]. The possible negative consequences because of stigmatization degree of asthma can be explained in terms of decreased self-efficacy in the management of asthma as well as the barriers it places on patients' access to health care and social relationships. Furthermore, these unfortunate implications may lead to the increased morbidity and a reduced quality of life of the asthma patients [5].

There is paucity in research regarding this issues of stigma in asthma patients [6]. This study aimed to address and explore the issue of stigmatization of asthma in asthma patient. In such cases exploring of the experiences and concerns of the patients is the right

strategy and way forward to deal the psychosocial concerns associated with asthma. The findings of this study will provide further insight in planning and developing strategies to deal with issue of stigma in both health care service settings i.e. hospitals and community pharmacies.

MATERIALS AND METHODS

In this study, eighteen adult asthma patients were approached for interview from two different health care service settings i.e. hospital and community pharmacy from Selangor, Malaysia. The two different study settings were selected so that dynamics of stigma of asthma could be thoroughly addressed because stigma of asthma has different dimensions that can vary in their influence from one study setting to other. Ethics approval was approved from the Research Ethics Committee (REC), Research Management Institute (RMI), UiTM Shah Alam and Medical Review and Ethics Committee (MREC), Ministry of Health (MOH) via National Medical Research Registry (NMRR). The Ethics Committee members were satisfied with all aspects of this study and approval was granted. Patients were informed about the range of matters relating to the research study they were considering to be involved before taking their consent. Any information that exposed the identity of the interviewee was avoided.

For this study, the qualitative study design was adopted because of its added advantage of flexibility and significant relation and roots in exploring the patients' experiences of stigma thoroughly and deeply. Furthermore, qualitative method in exploring stigma of asthma offered important insights that might have been missed by other research methods.

A semi-structured interview guide was developed and used during the interview process after thorough reviewing of the literature. The enrolled patients were interviewed using the pre-defined themes. The interviews focused on the following issues of stigma of asthma: stigma attached with disclosure of diagnosis, the possible discrimination because of stigma of asthma, personal adjustment

and adaptations to tackle stigma of asthma. The pre-testing of the interview guide was evaluated in six adult asthma patients; three from hospital and three from community pharmacy settings. Patients' demographic data was collected after taking their consent to participate in this study. In pilot study, same open ended questions were asked. In addition, the probing questions were used to draw required information from each respondent.

In real study, for each interview 20 to 30 minutes were allocated. Nine patients were interviewed at community pharmacy setting and nine interviewed at hospital setting. Patients' responses were recorded manually as well as electronically. The recordings were verified for its accuracy of transcription and then manually transcribed line by line for the relevant theme.

RESULTS

Eighteen patients participated in this study. A convenient sampling method was used to enrol the asthma patients. All patients were diagnosed as asthmatics according to Global Initiative for Asthma (GINA) guidelines, 2014. The majority of the interviewees were Malays, 10 (55.6%) and remaining 5 (27.7%) and 3 (16.7%) were Indians and Chinese respectively. The mean±SD age of the patients were 49.3 (±11.02) and among these majority were females 12 (66.7%). Furthermore, the mean±SD number of years being diagnosed as asthmatic was 13.85 (±10.87).

The main findings of this study identified three main themes. The contents and description of the themes were explained as following:

Theme one; stigma of asthma in terms of extent of disclosure about diagnosis status by the patients

The main focus of this theme was to explore the degree of denial to the diagnosis or hiding the diagnosis of asthma because of stigma. Overall, it was observed that newly diagnosed asthma patients and patients with mild asthma were quite reluctant to accept themselves as asthma patients.

Disclosure and denial to asthma diagnosis to friends and family

Patients had their own concerns for sharing their status and degree of denial to the diagnosis of asthma. Majority of the patients showed either denial or hiding the diagnosis of their illness.

I am not typical asthma patients. I have mild breathing problem and that occurs in some specific season only. I did not prefer to share my problem with all. It is of no need to share. But sometime it is not possible to hide because you have to take medicine in front of them. (AP6)

I shared it with my family as well as my friends so that if I have problem they can play their part. Regarding diagnosis, I am not depended on medicine because I rarely used inhaler and even if I do not use inhaler I can manage my breathing but with a little difficulty. (AP11)

For me it is no problem to share with my family members and some very close friends but other than them I do not want to disclose someone about my illness. As for as diagnosis is concerned no one asked me about this and I never prefer to tell by my own. (AP2)

Disclosure and denial to asthma diagnosis at workplace

Patients' disclosure of their illness at workplace was influenced by their job specification and patients' asthma status. If their asthma interferes with their daily duties at workplace, they prefer to disclose their asthma and vice versa.

Hmm, mostly when someone asked about my general health, I discussed my asthma problem. At workplace, I will prefer to disclose so that the employer should have a better idea about me and to hide it is of no use, I think. (AP9)

Theme two: Discrimination in the society because of stigma of asthma. This section has explored the extent of discrimination as a result of stigma of asthma.

Discrimination in the society because of asthma

Patients were asked about extent of feelings of discrimination observed at any particular occasion. Mostly, patients felt discrimination when their asthma limited them in certain activities.

Usually, have the feeling of being discriminated specially when participating in any event that involves physical involvement for instance playing outdoor games, going for jogging with friends especially in the morning or doing some physical task at home. This becomes worse when other persons put limits of your capabilities and underestimate you because of your disease. Sometime the excessive use of words for instance, 'like' 'but' and 'if' 'you could not', are always difficult to bear. (AP1)

Yes there is a definite discrimination especially when your friends are very good in sports and outdoor activities. You spend your most of time with them except the time they spend in the ground at that time. I experience the feelings of discrimination as well as isolation from the others. (AP4)

Not really. Mostly people were familiar with your problem so they never ask you to participate in any event which you could not. But deep inside sometime there is lacking a feeling of fulfilment and sense of limitation in such scenarios. (AP16)

In normal daily functioning few patients reported no feeling of discrimination. For them asthma is not the illness of being discriminated.

I didn't feel any discrimination in the society. Asthma is something normal, it's not like having HIV or HCV. No one is perfect; sooner or later, we all have limitations in our lives. So the thing that matters is how to adapt to that situation. (AP15)

Theme three: Patients' feelings affected by stigma of asthma and ways to adapt to the illness. The main aim of this section was to explore the feelings of asthma patients because of stigma and the strategy adopted to tackle their asthma and stigma attached with it.

Impact and Patients' adaptation to asthma in daily life

Patients described that how asthma influenced their lives and what was their response to those influences. Some patients accepted their illness and modified their lifestyles accordingly.

Asthma has made me stronger person. I take care my health more and stands tall in the society by staying as normal as possible. (AP15)

Few patients reported social isolation and avoiding the triggers of asthma.

I limit myself to myself. I tried to avoid public gatherings and any event where people can consider me as asthma patient. Beside this I also avoid the weather triggers of my asthma especially haze, my pet, dust and stress. Sometime, I have to overuse the inhaler so that I could improve my breathing especially in social events. (AP18)

Majority of patients found this hard to respond the situation in which someone asked about their illness. Ohh you know, this is the situation that I tried to avoid the most. If anyone discussed about this, I tried to change the topic or the best way is to find an opportunity to move out from that gathering. But if my asthma is under control, I feel more agile and comfortable in any situation. (AP9)

Some patients reported the influence of friends, family and health care professional as a deciding factor for their response to the illness.

It is ok with me. Most of my friends, tried to avoid any discussion that can highlight my limitations. So they are very supportive and with them, I never feel any type of disregard of having asthma. They understand me and my illness very well. My friends and my family members always make me as good and effective as normal person in the society. Beside this the response of the respiratory physician during my scheduled visits used to be very imperative. If the physician seems satisfied with the improvement then my confidence and positive energy also boosted up to manage the illness in a further better way and vice versa. (AP7).

The findings of this qualitative study manage to highlight stigma related issues of concern among adult asthma patients from state of Selangor, Malaysia. The patients' experiences of stigmatization were

common in both study settings i.e. community pharmacy and hospitals. The patients' adaptation to their illness needs to be given an in-depth consideration by both health care professionals as well as people from patients' close circle i.e. family members, friends and co-workers.

DISCUSSION

All the patients who participated in this study were adult asthma patients. They were diagnosed as asthmatic according to the Global Initiative for Asthma (GINA), 2014 guidelines [7]. In one recent study by Andrew and her colleagues reported the stigmatization degree of asthma in asthma patients and highlighted the adverse consequences of stigma in asthma patients [6]. In present study, majority of the patients disclosed at least two aspects of stigma of asthma. Some patients also reported the all three aspects of stigma i.e. discrimination, disclosure and perceived positive intensions. The presence of stigma in asthma patients can be very hazardous and may cause lot of irregularities in psychosocial life of the patient [3]. Asthma had a major impact on respondents' lives, disrupting their childhood, family life and career opportunities [8]. Furthermore, stigma of asthma has been linked with various triggers and protectors of stigma. Limitations faced because of asthma, social discrimination, isolation from the society, hidden fear of disclosure about diagnosis to others comes under the main triggers for stigma of asthma [9]. On the contrary, support from members of family, friends and health care system, better symptom control and self-management are the main protectors against high degree of stigmatization of asthma [10]. In addition to this, another part of the findings was that patients with asthma never feel good to have inhaler with them all the time. For them, the need of inhaler at any time is always problematic especially if they need to use it at their workplace, in public gatherings or in front of their friends who do not know about their illness [11]. Some elderly patients also reported the lack of interest and care by their children. They claimed that they were deprived of the care what they could expect from their children especially in the days of their uncontrolled asthma. So the carelessness of their children is the added stress factor that is responsible for deteriorate their psychosocial life. Some patients reported that they feel better once they made their scheduled visit to the hospital especially when physician said that they are improving well. This once sentence made them more satisfied and induce a power booster for their self-esteem. After visiting their physician they tried further to stay as fit as possible by improving their self-management.

There is a need to find out the strategies that can be employed to reduce the stigma of asthma in stigmatized asthma patients [12]. Furthermore, the relationship of stigma of asthma with other asthma control and severity parameters should be explored. Attempts should be made to instil positivity in asthma patients by community ridden education campaigns so that the stigma from the lives of

asthma patients can be uprooted and patients can enjoy their psychosocially active life in the community.

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CONFLICT OF INTERESTS

Declared None

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