Applying an ecological framework to examine the multiple levels of influence affecting the utilisation of private sector adult asthma services in Khartoum, Sudan: a mixed methods study [version 2; peer review: 1 approved, 1 not approved]

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Abstract
Background: Asthma is the third most common cause of hospital visits in Sudan. Sudan has a pluralistic health care system, with a strong and varied private sector. While research examining public sector asthma services exists, very little is known about which asthma services are available in the private sector.

Methods: An explanatory sequential mixed-method social ecological approach was used to examine influencing factors of asthma service utilisation in the private sector, considering five levels: policy, organisational, community, familial, individual environment. Quantitative research involved surveying private healthcare facilities to describe asthma services. Qualitative research involved in-depth interviews with asthma patients to explore facility decision-making. Nine private chest clinics, 44 pharmacies, and 21 private hospitals offering asthma services in Khartoum were studied - 46 female and 28 male health providers were surveyed; 7 male and 7 female asthma patients were interviewed.

Results: At the health policy level, there is no current asthma management policy for the private sector. At the organisational and health systems level, the survey found low rates of diagnostic equipment available, little asthma-specific training, and little use of asthma treatment cards, guidelines, and registers. At the community level, high levels of stigma from the community were felt by most of the patients interviewed. At the familial level, asthma was often viewed as a hereditary condition, and, as a long-term condition, there were worries about marriage potential and impact on jobs/future activities. At the individual level, patients sought frequent, short-term
care at private facilities for acute attacks. The severity of the disease and the major impact it had, particularly on younger adults', was striking.

**Conclusions:** Applying an ecological framework to examine asthma care management enables review of all levels of service provision: inclusive health policy, government commitment, high quality service delivery, uninterrupted affordable drug supply, community involvement, and patient empowerment.

**Keywords**
Sudan, Asthma, Health seeking, Access, Pathway to care
Asthma in Sudan: a growing problem

Asthma is a major health concern in Sudan, with an estimated overall prevalence of 8.7% of the population, more than double the global prevalence of 4.3%\(^6\). Excluding maternity and deliveries, asthma is ranked as the third most common cause of hospitalisation in the country, following pneumonia and malaria\(^7\). There was a striking rise in the number of emergency room visits by asthmatics between 1998 and 2004, increasing from 20,000 to 106,000\(^1\). While asthma is a concern for the Ministry of Health in Sudan, it is not listed as a public health priority. In the public health sector there are very few peak flow meters (which measure a person’s ability to breathe out air) for diagnosis, few drugs available, and few staff trained in asthma management\(^8\). Many health professionals working in both the public and private sectors are not trained in tackling chronic asthma or long-term management of the disease\(^9\). This combination of factors leads asthma patients to seek care in the private sector. Research on asthma management in Sudan, conducted in 2003, found that 95% of patients paid the full cost of their asthma medicines; less than 2% of them received regular treatment from a single facility, and patients typically had no knowledge of their asthma management plan\(^1\). In a country where the daily wage of the lowest paid, unskilled government worker is USD $2.20 per day, the cost of one day of hospitalisation for asthma is USD $79.60, with patients also responsible for the cost of medicines and other additional costs\(^1\). These high costs of healthcare and medication often result in asthma patients self-managing their condition and only seeking care when they are extremely ill.

A pluralistic health-care system in Sudan

Partly as a result of low confidence in the public health sector in Sudan, a pluralistic health system has grown and healthcare is provided by both the public and private sectors\(^1\). The government levels of funding for the public health sector is low at 6% of the GDP (gross domestic product), well below the 9% recommended by the World Health Organization (WHO), with high out-of-pocket expenditure by individuals, estimated to be above 60% of monthly salary\(^10\). The private sector includes ‘not for profit’ and ‘market based/for profit’ health-care facilities, and has expanded rapidly in the last 10 years\(^11\).

Asthma as a leading cause of hospital emergency room visits

Untreated asthma and poor management of the disease can lead to frequent visits to hospital emergency rooms\(^1\). There are many factors that lead patients to seek care in the emergency room, including asthma severity, incorrect perceptions of the disease and its medication, lack of an asthma treatment plan, over-reliance on short acting bronchodilators, changes in weather and pollution, as well as education and socioeconomic levels. Avoiding crisis care of acute asthma through long-term management and reducing the use of emergency rooms for acute asthma treatment are major goals of asthma management\(^12\). To examine this issue, changes in hospital admissions over time may be used as an indirect indicator of the burden of severe asthma\(^10\).

Introduction

Asthma in low and middle-income countries

Respiratory diseases now account for 17.4% of all deaths in sub-Saharan Africa\(^1\). In 1990, there were 74.4 million reported cases of asthma in Africa. This figure rose to 94.8 million cases in 2000 and 119.3 million in 2010\(^2\). However, due to low levels of accurate diagnosis, the true prevalence of the disease is expected to be much higher. It is estimated that the number of cases will continue to increase from the currently estimated global prevalence of 330 million to reach 400 million by 2025\(^3\).

The majority of people living with asthma in low and middle income countries (LMICs) have very limited access to essential prevention and treatment\(^4\). There is a high financial burden on individuals living with the disease, on their families, and on health-care systems at-large\(^4\). Inadequate treatment, coupled with high financial healthcare costs often results in high levels of disability, absenteeism, and increased risk of poverty. If the disease is left untreated, it can become much more severe and result in hospitalisation, or, in poorly controlled cases, become fatal. Severe uncontrolled asthma results in frequent hospitalisations and emergency room visits, disproportionately affecting individuals of lower socioeconomic status\(^5\). The total cost of asthma treatment and care is estimated to be at least USD $20 billion annually in LMICs\(^5\).

In addition to a lack of political commitment and a chronic shortage of asthma drugs in LMICs, there is also the issue of weak health-care systems that are unable to support patients, particularly for chronic diseases\(^6\). Other key obstacles to asthma care are availability of equipment, poor chronic care education of health-care workers, weak asthma case notification/referral systems, and issues in implementing long-term care in a poorly functioning health-care system\(^7\). In addition to weak health-care system support for asthma patients, it has been shown that there are sociocultural misconceptions attached to the disease and to the use of inhaled steroids, which significantly affects adherence to treatment\(^7\).

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individuals, households, health institutions, the wider socio-cultural environment, and the subsequent influence these have on decision-making and on understanding health-care utilisation behaviours. This research looks at the interaction between these levels of influence: individual, interpersonal, societal, organisational, and policy.

Methods

Study design

A two-phase approach was developed that would combine an identification of systemic factors driving private health-care choice and a mapping of the process involved in healthcare seeking. A quantitative health-care facility questionnaire took place from April 2014 to December 2014 and collected information on asthma services available from a large number of private facilities (breadth). Qualitative, in-depth interviews which took place from September 2014 and March 2015 explored in more detail the process and rationale of health-care decision-making of adult asthma patients (depth), with a focus on their individual decision-making regarding public or private care, and their complicated healthcare seeking process.

Stage 1: quantitative data collection

The Ministry of Health in Sudan provided a list of all the private facilities in Khartoum city that were listed as registered in 2014 (year of the data collection) and which facilities offered asthma services. Of the registered private health facilities that provided asthma services in 2014, there were 21 private hospitals, 9 private chest clinics, and 444 private pharmacies. Pharmacy providers were stratified according to location and randomised. The sample size for the survey was determined with a 90% confidence interval rate, and a precision estimate of ±15%. A random sample of 10% from each sub-district was chosen for the survey. There were 444 registered pharmacies split across three sub-districts of Khartoum (302 in Khartoum sub-district, 78 in Alshodha, and 64 in Khartoum East). Each of the three sub-districts were randomised separately using Excel to account for the difference in number of facilities. A random sample of 10% from each sub-district was chosen for the survey. Table 1 shows the number of health facilities included in the study (n=74).

Figure 1. A social ecological approach: multiple levels of influence in health-care behaviour. Adapted from Shahabuddin et al. under the terms of the Creative Commons Attribution 4.0 International license (CC-BY 4.0).
In order to answer the questions on access to asthma treatment, the survey focused on the following categories: Availability: levels of trained asthma health workers, asthma drugs, registers, guidelines and asthma diagnostic equipment; Accessibility: Understand the rate and type of use of services by asthma patients; Acceptability: Provider perspectives of the health-seeking behaviour of patients who use the private sector.

The research team used smartphones, which stored the questionnaires, to input responses given by the health-care worker. The use of electronic questionnaires has been shown to improve collection time and accuracy, when compared to paper questionnaires\(^1\).

The private health providers were visited on an individual basis at their health facility (private hospital, clinic or pharmacy). At each health facility, the Senior Manager was met and asked for permission to conduct the research. They were then asked for the names of the health workers who fulfilled the inclusion criteria. One health care worker at each participating health facility was surveyed. The inclusion criteria for the survey: the provider provided care to adult asthma patients; they consented to be surveyed; they had regular contact with asthma patients and they provided an asthma diagnostic or treatment service for a fee.

**Stage 2: in-depth interviews with asthma patients**

The second phase of the research was based on models of healthcare seeking qualitative research\(^2\) and built on the findings of the Phase 1 provider survey. Exploratory qualitative research with asthma patients who sought care in the private sector in Khartoum was conducted using in-depth interviews.

**Identification of participants and data collection in the qualitative component.** During the health facility surveys, 14 asthma patients were identified and agreed that they would be willing to be interviewed. Table 2 shows the number patients interviewed, disaggregated by age and gender. The providers included in the Phase 1 quantitative survey assisted with identifying patients who attend their centre for the Phase 2 qualitative interviews. They were also informed that the interviews would be anonymised so that it would not be possible to tell which patients were talking about which health facility. The providers were briefed on the inclusion criteria and were asked to try and select a cross-section of patients according to age and sex.

The inclusion criteria for the in-depth interviews was as follows: They were aged 18 years and above, self reported to have an asthma diagnosis, live in Khartoum state, self reported to have sought asthma care at a private facility (hospital, clinic or pharmacy) and consented to be interviewed. It was aimed to try and interview a balance of ages and an equal mix of male/ females. The purposive sampling frame set out that four patients would be selected from each of the three provider categories (hospital, clinic, pharmacy) with an even split of males and females.

However, this method of selection had the potential to lead to bias (such as people who are expected to give positive responses being selected by the gatekeepers), but this was felt to be the most feasible and convenient sampling method.

In order to avoid coercion, information about the study was given out by providers but patients contacted the researcher not the provider to express interest in the study, to ask questions about it and consider participation. They signed a consent form to demonstrate they were happy to participate. The patients chose whether they would prefer to be interviewed in their home, at the Research Centre or at the health facility. The interviews were recorded using dictaphones and then transcribed in Arabic by the data collection team. These transcriptions were translated into English and checked back into Arabic for consistency and accuracy of translation.

<table>
<thead>
<tr>
<th>Type of health facility</th>
<th>Survey respondents</th>
<th>Job specialism</th>
</tr>
</thead>
<tbody>
<tr>
<td>Private hospitals</td>
<td>19 doctors (11 women, 8 men) 2 nurses (1 male, 1 female)</td>
<td>General hospital doctors General hospital nurses</td>
</tr>
<tr>
<td>Private chest clinics</td>
<td>9 doctors (3 women, 6 men)</td>
<td>Chest physicians</td>
</tr>
<tr>
<td>Private pharmacies</td>
<td>44 pharmacists (31 women, 13 men)</td>
<td>Pharmacists</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>74</strong></td>
<td></td>
</tr>
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</table>

**Table 1. Type of facility surveyed.**

<table>
<thead>
<tr>
<th>Total, n</th>
<th>Age, years, n</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>18-30</td>
</tr>
<tr>
<td>Women</td>
<td>7</td>
</tr>
<tr>
<td>Men</td>
<td>7</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>14</strong></td>
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**Table 2. In-depth interview participants.**
The interviews took 40 minutes and focused on individual healthcare seeking behaviour for their asthma, experiences of seeking care in the private sector, and their opinions about how their family viewed their condition, as well as the wider community thoughts regarding asthma. Due to time limitations, it was not possible to interview community or family members about their opinions on asthma care and private sector provision of care.

Each individual was given a unique identifier number, comprised of a reference number, age, and gender. Each quote below is followed by a code that stands for gender (M/F) and the interviewee’s age. No two people were the same age and gender. The interviews were recorded with the patient’s consent. The interviews were transcribed by the research team in Arabic. These transcriptions were then translated by professional translators and then a sample were back translated to check for translation quality. The research team consisted of three experienced Sudanese qualitative researchers (two women and one man). Only one researcher was present at the interview. A topic guide was used to prompt and guide the interview: a copy of this is included in the extended data section.

**Data analysis of the qualitative interviews.** A three-step thematic analysis was conducted on the qualitative data\(^1\). Key themes were identified through reading of the transcripts. Interview transcripts were organised using NVIVO 11 software and linked to patient demographics. Concepts and labels were applied using a cross-sectional ‘code and retrieve’ approach\(^2\). This gave a systematic overview of the scope of the data and enabled us to make comparisons and connections.

Data were anonymised and stored securely throughout. Safeguarding of participants was prioritised throughout study design and implementation.

**Ethical approval**

Ethical approval for the study was obtained from the National Health Research Ethics Committee (NHREC reference 17/7/14) in Khartoum, Sudan and the Liverpool School of Tropical Medicine Ethics Committee, United Kingdom (reference: LSTM REC 13.33). All participants gave written informed consent to participate in the questionnaire and interviews.

The participant information sheet and consent form both included statements about the possibility of publication of anonymised interview content. All participants gave their consent for the publication of material obtained in the interviews by signing the consent form.

**Patient/public involvement:** Health-care providers, policy makers, and asthma patients were consulted in the development of the research and provided feedback on the findings of the pilot stage. Specifically, they provided input into the types of questions that were best suited to the quantitative survey, and which areas would fit best in the qualitative interviews.

Asthma patients gave their full written consent to be interviewed, as well as commenting on the findings and dissemination plan. The research was disseminated at a public meeting in Khartoum in April 2018, which was attended by asthma patients, policy makers, academics, and health-care providers.

**Results: Applying the ecological framework to the findings**

**Health policy level**

Government commitment to asthma as a priority health condition is highlighted in international guidelines as a key factor for improving health outcomes\(^1\). There is now a high level of international political support for an increased focus on asthma\(^2\). This support needs to filter down to the regional and country level, and lead to countries prioritizing asthma control through improved access to essential drugs, technologies, and well-trained medical personnel. Sudan does have a national asthma strategy. However, this focuses on the public sector and has only been loosely applied in practice\(^3\). This is consistent with other countries, where there has been limited adoption of international guidelines in resource-poor settings\(^4\). Implementing standard case management and strengthening health-care systems at all levels should be advocated for by the different stakeholders involved in asthma care\(^5\).

According to the International Asthma guidelines\(^6\), once an asthma diagnosis is made, a patient should receive an asthma management plan. This guides the patient on how to take their medicine and which inhalers to use, as well as how and where to seek care. These plans have been shown to lower the need for emergency care and lessen the number of severe, life-threatening attacks\(^7,8\). None of the patients interviewed had such a plan and all described very complex journeys to seek care. Most of the patients only sought care when they were experiencing an attack.

**Organisational and health system levels**

Strengthening all components of the health-care system (public and private) is key to overcoming the barriers to effective asthma management and control. Good asthma management requires an uninterrupted supply of high-quality, affordable medicines, well-trained health professionals, effective diagnostic technologies, appropriate asthma guidelines, and registers to ensure accurate information recording and well-organized health-care services\(^9\). This study found that, in the private sector of Sudan, many of these essential requirements were lacking.

**Diagnostic equipment.** According to the International guidelines, asthma diagnosis is conducted using a peak flow meter and clinical assessment\(^1\). A low percentage of hospitals reported having asthma diagnostic equipment (31% had a peak flow meter and 27% had a spirometer whereas a higher proportion of the chest clinics had diagnostic equipment available as shown in Table 3.

Spirometry can also be used for asthma diagnosis but it tends to be more helpful in understanding other lung health conditions that can often be disguised as asthma and these devices were more common at the private clinics rather than at the hospitals\(^2\). None of the pharmacies offered diagnostic services and so did not have peak flow meters or spirometers.
The low rates of spirometers and peak flow meters in hospitals are not unusual and are comparable with other low-income countries. The low rates found in the private sector were still higher than in the public sector, where there is very little asthma diagnostic equipment available. The lack of definitive diagnosis can lead to over/under diagnosis of the condition and rely on the diagnostic skill of the health-care provider.

Asthma registers. Asthma-specific registers and guidelines were in low supply in all of the facilities. Only one hospital and one clinic reported using an asthma specific register and none of the pharmacies kept asthma registers. Asthma guidelines were more widely held at half of the facilities. Very few of the facilities surveyed used specific asthma treatment registers and relied on the standard Ministry of Health outpatient registers to record asthma patients. International guidelines recommend the use of standardised asthma registers and the use of asthma treatment cards to assist with asthma management. These were not found in the majority of the private sector facilities surveyed in Khartoum, which makes it difficult for health-care providers and policy makers to assess the number of people receiving asthma care.

Health-care provider training. A key component of asthma management guidelines is asthma-specific training for health-care personnel. The health workers surveyed at the facilities all received training themselves on asthma as part of their general medical or pharmacy training, but only 4 of the 21 (19%) health workers at the hospitals and 3 of the 9 (33%) health providers at the clinics had undergone specific training on asthma since qualifying from medical school. One pharmacist reported asthma specific training which was carried out at Khartoum hospital. The hospital health providers’ training focused on asthma management in the emergency room and as an acute condition. The doctors at the clinics had a broader training on lung function tests and inhaler technique. Asthma is a complicated disease to diagnose and treat. Furthermore, it consists of both acute attacks and chronic symptoms. Therefore, specialist training is recommended to ensure patients are given the best support for managing their disease.

Asthma drugs. Patients highlighted that the availability of drugs was a major issue, particularly in the public sector. The cost of drugs was also viewed as a key barrier to managing their disease; both patients and providers cited that cost was the main reason for stopping treatment. When the public sector has a low availability of drugs, as seen in the public provision of asthma drugs in Khartoum, the use of the private sector increases. A lack of legislated price control has led to wide variation in prices and was mentioned by patients as a motivator in where drugs were purchased. There are other considerable costs, such as consultation fees, hospital admissions, complementary treatments, and laboratory tests.

All of the 21 hospitals and 3 of the 7 (33%) clinics said that they stocked asthma drugs. All the pharmacists reported stocking a range of asthma drugs. 34 of the 44 (77%) pharmacists reported stocking all 5 recommended asthma drugs (anti-inflammatory drugs, bronchodilators, beclomethasone, salbutamol, budesonide). There was a large variation in the cost of the drugs between pharmacies as listed in Table 3. This is mostly due to a difference in branded and generic versions of the drugs; branded, international brands have a far higher cost than Sudanese generic drugs. Average daily salary in Khartoum is 122 Sudanese pounds, the average price of the reliever inhalers was around 20% of a daily salary while the preventer inhalers were between 35% for non-branded types rising to over a day’s wage for the branded versions drugs, as shown in Table 4.

Asthma health education. Access to quality of health information regarding health-care providers and disease specifics has been shown to affect provider choice. There was a distinct shortage of asthma leaflets or posters. The importance of education in inhaler technique was also highlighted as a key factor affecting patients’ treatment. Increasing the role of pharmacists beyond asthma drug dispensing, to patient counselling and education, could act as a way of improving inhaler technique, thus reducing improper use and the accompanying occurrence of severe attacks.

Community and cultural levels

Communities play a key role in asthma management and shared beliefs often influence healthcare seeking behaviour. Stigma in communities was reported by patients and resulted in delayed healthcare seeking and case management. Stigma was particularly of great concern for younger women who reported that people treat them differently when they find out that they are asthmatic. People in the community feared that asthma is contagious or believed it to be disgusting. It was felt that it could affect marriage potential, as people do not want to marry someone with a long-term condition. Due to inhalers being perceived as

<table>
<thead>
<tr>
<th>Type of Facility</th>
<th>Spirometers</th>
<th>Peak Flow</th>
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<tbody>
<tr>
<td>Hospitals</td>
<td>6/21 (28%)</td>
<td>7/21 (33%)</td>
</tr>
<tr>
<td>Chest Clinics</td>
<td>7/9 (78%)</td>
<td>8/9 (88%)</td>
</tr>
<tr>
<td>Total</td>
<td>13/30 (43%)</td>
<td>15/30 (50%)</td>
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<thead>
<tr>
<th>Drug</th>
<th>Price Range (Sudanese pounds)</th>
<th>Mean Price (Sudanese pounds) (SD)</th>
</tr>
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<tbody>
<tr>
<td>Anti-inflammatory</td>
<td>2 – 50</td>
<td>12.87 (15.98)</td>
</tr>
<tr>
<td>Bronchodilator</td>
<td>4 -90</td>
<td>26.17 (13.96)</td>
</tr>
<tr>
<td>Beclomethasone</td>
<td>3 – 168</td>
<td>42.60 (49.94)</td>
</tr>
<tr>
<td>Salbutamol</td>
<td>5 – 42</td>
<td>25.34 (10.60)</td>
</tr>
<tr>
<td>Budesonide</td>
<td>25 – 260</td>
<td>124.69 (82.63)</td>
</tr>
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addictive, people who use them can be viewed by the community as addicts. As with the individual concerns, these societal concerns were felt more strongly by younger patients and, in particular, by younger women.

The influence of community views of asthma was reported strongly and by many of the interviewees. People reported a low level of understanding in the community of the disease and how it can be managed successfully. They also highlighted little knowledge in the community as to the causes of the disease. Many of the patients described how people treat them different when they find out they have asthma.

‘People are afraid of asthma because they think the patient will have an asthma attack if he gets into a small argument. But it is the opposite and he is normal like everyone else. – people are afraid of arguing with asthma patients’. (M21)

These commonly held beliefs were not always accepted by the patient themselves but they felt the beliefs were so strongly held in the community that there was little the individual could do to change these beliefs. It often led to a delay in diagnosis and a delay in treatment.

The disease was often viewed as contagious, and therefore changed how people interacted.

‘there are some people who are scared of the disease they say it’s contagious’ (F30)

Some of the younger women also reported that because asthma is a long-term condition, people in the community perceive the disease to have a long-lasting impact on the patients’ futures.

‘there are people frankly when they would approach you for marriage and know that you have asthma, they will be afraid and will say that she will always be taking me to doctors and even the children when they are born then might have asthma because of the weather…if someone wanted to marry you then if they know you have asthma, they will say that she has asthma and that she will take me to the doctor all the time so I better find someone who is healthy.’ (F30)

The use of an inhaler in public was also described as something that people were cautious about, particularly younger men and women. One mother reported that her daughters were viewed negatively when they used their inhaler in public. While the mother knew the benefits of inhaler use, she highlighted that the broader community held stigmatised views of them.

‘they will ask me why do I insist to say that my daughters have asthma and they refuse and they say that one of them will be addicted to the treatment. All of that is not correct and in contrary if one takes the medication then it will become less’ (F45)

There was the assumption that the community as a whole believed the best method of treatment was treating an acute attack at the hospital emergency room.

‘Asthma is known, everyone knows it, as soon as I get an attack, they prepare the car and take me to the emergency room.’ (M60)

The stigmatisation of inhaler use is compounded by society’s view that the best method of treatment is at hospital emergency rooms. This fits with the low level of preventer inhaler use amongst the interviewees and their repeated visits to hospitals for acute care.

Familial level

Many of the patients highlighted strong family links with the disease. Yet, patients still preferred to refer to their condition as an allergy. They also described how common the disease is in Khartoum, and that it was very difficult to find someone who was not affected (despite the stigma surrounding the disease). This is consistent with the finding that asthma is the third most common reason for seeking hospital care in Sudan, and how over-burdened the health-care system is with asthma cases.

Many people reported that inherited factors played a key role in their asthma condition, and that this was the main causal factor of their condition. Genetics and family history were mentioned by over half of the patients:

‘There is no problem in the family, we are in an asthma forest, my mother, grandmother and uncles have asthma. So this is a very normal thing in because it already exists in the family.’ (M48)

It led to a sense of feeling that there was little that could be done about the disease and that they should just accept living with it. The belief that asthma is hereditary is so strongly held that one young woman described the shock of being the only person in her family diagnosed with the disease.

‘By god the people of my house were very shocked, to be frank with you, the shock for them was abnormal as there is no asthma in the family. We have not anyone having asthma in neither my father’s nor my mother’s side… Of course we were told it was asthma, then they said where has she got this illness from? At the end of course they can say nothing as it is from God almighty.’ (F36)

Family members were reported as key in the decision-making process about where to seek asthma treatment. Often, the decision was made entirely by the family if the patient was too ill and needed to be treated in an emergency situation. Involving patients’ families in health promotion activities could be a successful way to improve health education and knowledge about the disease. Further work that delves deeper into this and understands the relative roles different family members play is recommended.

Individual level

Health beliefs affecting choice of provider. Most patients described knowing very little about asthma before their diagnosis, except that they believed it was caused by an allergy or is
an inherited condition\textsuperscript{15,36}. Refusing the diagnosis, and relying on the self-diagnosis of allergy, affected choice of provider and management of the disease, particularly for the younger women interviewed, and links with the increased levels of stigma in the community faced by these women.

Whether asthma is viewed as separate acute episodes or a long term chronic condition seemed to influence how people sought treatment and how they perceived it affected their lives. While many respondents acknowledged how common the disease was in Sudan, they often preferred to refer to it as an allergy rather than a long-term condition. The use of the Arabic word ‘hassaseeiaa’ rather than ‘asthma’ was an indication about the reluctance to accept asthma as a diagnosis. There was a belief that an allergy was something that could be treated and was short term whereas asthma was a lifelong condition that had social and physical consequences. The patients described that there was a reluctance by health workers to discuss asthma and preferred to diagnose it as an allergic reaction.

‘Even the health workers .. use the word ‘hassaseeiaa’ [allergy], they start stigmatizing, especially when you find you are a woman who is younger. They say you have a chest hassaseeiaa without using the word asthma….There are people who will hide that they have asthma, there are some who will be shocked and they will say it is allergy.’ (F18)

Treating asthma as an allergic meant that many of the patients, especially female ones, only sought care when they had an attack. The stigma regarding an asthma diagnosis extended to stigma regarding the use of inhalers in public and this was highest for younger women. They reported that they would rather not use their inhaler when in public, and that if they did, it would bring unwanted attention:

‘By God, frankly doctor when I got this disease and they gave me the three inhalers, I was very sensitive and I was not able to carry my inhaler with me. As we were going out and she [mother] was telling me to take my inhaler and I was very sensitive about this issue, so I told her that I can’t take the inhalers. Do you want me to puff in front of all the people? So I said I will never puff in front of people’. (F36)

High levels of stigma regarding inhaler use can have a big impact of the lives of people living with the disease. Not using inhalers regularly mean that attacks are often more severe and more dangerous and need hospitalisation.

Perceptions of care quality. Patients perceived a higher quality of care in the private sector. It was found that the public sector was viewed as overcrowded, with long waiting times, and sometimes low levels of hygiene. This was a major motivator for seeking care in the private sector. Service quality was also viewed by many individuals as much higher in the private sector.

Most patients reported that the main difference between public and private care was that the public sector facilities were very overcrowded. They reported that they would often have to wait a long time for an oxygen machine as there were often two or three people waiting for each machine.

‘The public hospitals are crowded. Eight or ten years ago I went to Alnaw, when I went I found they have one oxygen machine with Ventolin. I wait because there are two or three people in front of me. In that moment you will be annoyed but in the private hospital, they have a number of machines and beds.’ (M60)

Public hospitals were often described as not being clean enough and chaotic when compared with private facilities and this was a motivating factor for not seeking care in the public system. Location was also a key theme affecting the choice of provider. This was varied and depended on the severity of the attack. In a severe attack, the nearest facility was chosen.

‘this [private] hospital is close to us and they will save me faster. The private hospitals have solved many problems especially for the asthma patient. The public hospitals are cheap, but there are many things that are not available.’ (F18)

Patients also expressed that they would choose a health provider that was known to them and that the private sector was always their first choice:

Healthcare seeking behaviour. The main reason patients reported seeking care was due to extreme illness. The severity of the disease, and that it often causes death, was a source of great concern for the patients. Many reported that they knew someone who had died of the disease and that they themselves had become unconscious from an acute attack. These attacks meant that short-term, fast acting treatment was sought, and so the patients went directly to the hospital emergency room (often repeatedly). Severity was a theme that came out strongly and was consistent with the health facility survey that highlighted many people sought care when their asthma was urgent and life threatening.

‘Asthma puts you in a bad psychological state, you confront death, this is the only disease that makes you feel that you are about to die. And when you are treated you will be in a very bad psychological state because the asthma patient is always stressed, whether he has an attack or not. He can get an attack at any time. This is why I think the asthma patient is always at the edge of his life…’. (M48)

‘I mean seriously this thing was a big obsession for me; it is a fatal disease and should not be taken lightly ….Like I gave up on life, I will not lie to you, it is like you find out that you will die soon, it is in God’s hands’ (F30) (after being asked how she felt when she received her diagnosis)

The association between asthma and death is strongly held by a broad range of age groups and across both genders. This affected choice of provider as care was sought urgently in an emergency setting rather than as routine management of the condition. In Sudan, these patients all described their fear of asthma
related death and how they focus on treating their attacks as a series of acute episodes rather than a chronic condition. Accessing care and provider choice for acute attacks can be quite different to long-term management of a condition. The majority of people sought care because they were extremely ill, and the decision as to which facility to seek care in was not made by the patient, but by someone else (a family member or neighbour).

‘they lifted me up as I was completely comatose, and I was not breathing at all so my family supported me and they started shouting and the neighbours came and helped with lifting me up, our neighbour took me in a rush to the hospital’ (F36)

The impact asthma had on the patient’s daily life was strongly articulated, with most people describing high levels of worry and concern and how it disrupts their plans and is an obstacle to carrying out a normal life.

‘My feeling was extreme anger because he [the doctor] forbade me from playing football and grasshoppers and dust and such. I used to work with my uncle during the holidays as a building labourer, he forbade me from all of that, I just sit in the house, bored’ (M29)

‘Sometimes I would find myself collapsing because I got tired but I can only thank God, I have stopped from my studies. This illness needs follow-up and to know how to know the use of the medication’ (F30)

‘I am scared and worried when I have an infection, I will not be awake, not among the living and not among the dead’ (F36)

The younger age group (both males and females) described higher levels of concern about having the disease and that it majorly impacted on their daily lives causing them to stop doing certain activities.

Healthcare utilisation. A strong finding was the frequency with which patients sought care for their asthma and that the hospital emergency room was the main place where they sought care. An acute attack altered choice of provider as the nearest accessible facility was chosen, whether it was private or public. Self-referral to upper level health care facilities is often a result of a perception that primary care facilities offer low-quality care and a lack of available drugs or personnel11.

According to the International Asthma guidelines12, once an asthma diagnosis is made, a patient should receive an asthma management plan. This guides the patient on how to take their medicine, which inhalers to use and how and where to seek care. These plans have been shown to lower the need for emergency care and lessen the number of severe, life-threatening attacks12. None of the patients interviewed had such a plan and all described very complex journeys to seek care. Most of the patients only sought care when they were experiencing an attack. This care ranged from using a home oxygen kit to having to go to the hospital emergency room for treatment. For some of the patients, the journey meant that they had to seek care outside of Sudan.

Repeated visits affect the patient’s ability to live a full life and also come with high levels of financial costs. This woman describes going to the hospital to receive oxygen five times a month and has to pay each time.

‘There is supposed to be discounts as the attack can happen to the patient about two times in a week. And the oxygen room is for 40 pounds, in a month if I got sick five time, it is too expensive. For me it is a continuous asthma and any minor thing can affect me, dust or heavy wind and also if I made a great effort or I got mad because of a situation then I will not be able to breathe’ (F30).

In the majority of asthma cases worldwide, the use of preventer inhalers substantially reduces the number of hospital visits and reduces severity of attacks. Most people only described the use of oxygen and reliever inhalers such as Ventolin. Only a few people reported ever having used a preventer inhaler but those that did felt that they were very beneficial.

‘Before I came here I used to suffer a lot, each week I stay two or three days at home. I told him [Doctor] my history with asthma and he gave me the preventer, since then I feel a lot better. I am a completely new person after I started taking the preventer’. (M48)

The cost of both types of inhaler was highlighted as a major reason that people did not use inhalers. While for some people the high costs meant that they would not use the inhaler, others reported that they would prioritise affording it over spending money in other areas as demonstrated by the quote below:

‘By God it is not good, but thanks God what can we do about it, everything is becoming very expensive and this [inhaler] is the only thing that has to be always in my hands and I can stop eating or drinking, but the inhaler has to be in my hands’ (F36)

There were a lot of costs reported in addition to the price of the inhalers, such as the use of the oxygen room, injections, hydrocortisone, doctor consultation fees, and these were considered as barriers to sustaining effective asthma management.

Another person reported that he often saw a person begging on the street outside an asthma hospital asking for inhalers, and sometimes he would try and help by buying an extra one.

‘I saw people who beg for the inhalers in Hawadith street, he [one man] brings the receipts and tells you that he wants an inhaler because his inhalers are finished. Sometimes I buy it for him’...(M60)

Most patients self-managed their condition and sought care when they felt they needed it. Self-medication was viewed as a low-cost alternative to health-care facilities, which charged consultation and laboratory fees. Those interviewed had no treatment plan or guidance on the steps to take to avoid asthma attacks. However, they felt they knew what to do to reduce the
frequency of attacks, and on the whole, avoided going to see doctors for advice. This study did not find strong gender differences with both men and women describing managing their asthma themselves. Age did seem to be a factor with more people mentioning self-medicating who were over 30 years old and only a few under 30 years.

'It has been years since I saw a doctor...I just use my inhaler. I control my asthma and avoid infection and flu. Last time I saw a doctor was in 2000/2001' (M60)

The use of inhalers to treat an attack was accepted, but preventative inhalers were used much less often. Pharmacists were the main point of contact for those who were self-medicating, and it is proposed that they play a key role in providing advice to consumers on the safe use of drugs and on inhaler technique.  

Discussion

Using a social ecological approach has offered an understanding of the different levels that influence asthma service delivery in the private sector in Sudan, as well as how and why asthma patients utilise these services. The phased mixed-method approach gathered complementary data to provide a fuller understanding of if, where, why, and how asthma patients seek care. The findings described above highlight that choice of provider and management of disease is more than supply and demand; decision-making involves multiple levels of influence and different perspectives that incorporate severity and health-care consequences, and that these factors all interact to affect health outcomes.

Adopting a social ecological approach to examine asthma health-care seeking behaviour and provider choice facilitates understanding regarding which factors influence decision-making by asthma patients in Khartoum. Decisions regarding asthma treatment are influenced by age, severity of disease, and perceived quality of services.

A key part of successful asthma management requires patients to be empowered so that they have a good understanding of their condition, a willingness to accept the diagnosis, and a supportive social environment, thus giving them the ability to treat the condition between attacks. Health-care choices in Khartoum are currently made on an attack-by-attack basis, and short-term, acute care is sought, rather than long-term management of the disease. The private sector, while viewed as expensive, is also viewed as having a higher quality of care, with treatment being delivered faster, which is vital in the case of an acute attack.

Organisational and health-care system issues, such as a lack of available and affordable drugs need to be addressed alongside increasing demand for services and perceived quality of care administered by different providers. Asthma programmes need to promote the benefits of long-term management of the condition. Specifically, how it will reduce the frequency and severity of attacks, reduce hospital admissions, and should lead to individuals living a more normal life. Implementing the International Guidelines for Asthma Care in Khartoum in the private sector would be very beneficial addressing the different levels, including political commitment, drug availability, training, and diagnostics. Pilot studies in Sudan have shown that implementation of standard case management systems in the public sector can be very beneficial in reducing hospital visits, and have recommended a more extensive rollout of these systems.

Strengths and limitations of this study

Asthma is a severe disease that acutely and chronically affects many people in Sudan and the accompanying region. It places a large burden on a weak healthcare system and causes severe distress for those suffering from the disease. Previously, very little was known about the health seeking behaviour and service provider choice for asthma patients. A strength of this paper is that it highlights that the pathway to care is complex and there are multiple influences on decision making. Young people, especially young women, face enormous stigma from having the disease, affecting their choice of provider and treatment options, especially with regard to a reluctance to use preventative inhalers.

The current practice of seeking care at hospital emergency rooms is a result of the severity of the asthma attacks and a lack of knowledge of alternative options for care, leading to an overburdening of emergency rooms and lack of trust in outpatient facilities.

A limitation of this paper is that due to time and funding restrictions, this study did not interview community members with regard to their attitudes to asthma patients. This could have given more insight into the reasons behind the stigma felt by the patients. Another limitation is that the interviews rely on individuals reporting their own asthma diagnosis. Therefore it is possible that they may have an incorrect diagnosis and could be affected by other conditions but their health seeking experiences would remain informative. The interviewees were also not asked about the clinical severity of their asthma as many were unsure of this as they did not have asthma treatment plans.

Conclusion

Encouraging private sector providers to implement standard case management should lead to a reduction in emergency room admissions and less severe attacks, as well as reduced asthma related fear and concern on the part of patients. The reasons behind patients’ choice of healthcare need to be addressed alongside the provision of appropriate services to improve outcomes for asthma patients. Targeting all layers of influence on health-care seeking and provider choice is the most likely to create sustainable health improvements.

Data availability

Underlying data

Due to the level of detail in the qualitative transcripts from this study (stage 2), even with direct personal identifiers removed, the stories and descriptions of participants within the transcripts makes them potentially identifiable, as well as containing sensitive and confidential patient information. We do not have
References


Acknowledgements

This study has been made possible by the team at Epidemiological Laboratory for Public Health and Research (EPI LAB), Khartoum. We are extremely grateful for their collaboration and support throughout. We would also like to express sincere thanks to all the participants of the study, who kindly gave up their time to be interviewed and who provided such helpful and informative insights into their lived experiences of accessing healthcare in Sudan.

This study was part of the PhD thesis ‘Multiple levels of influence affecting the utilisation of adult asthma services in the private sector in Khartoum’ written by RT. The full thesis is available here: https://doi.org/10.17635/lancaster/thesis/538

Registered on 28 September 2020 (osf.io/v3j7x).

This project contains the following extended data:

- Questionnaires.docx (Facility structured survey; quantitative study 1)
- Topic guide.docx (Interview guide; qualitative study 2)

Data are available under the terms of the Creative Commons Zero “No rights reserved” data waiver (CC0 1.0 Public domain dedication).


Elopy N. Sibanda

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The authors have addressed the points raised in my previous review satisfactorily.

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Asthma, Allergy and Clinical Immunology

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.
The situational context of the study is clearly articulated in the introduction.

The mixed methodology that brings together quantitative and qualitative aspects has its merits, however it may cloud the message. Each aspect, is important however the qualitative and quantitative analyses can down play the overall findings.

The authors address an important issue of the occurrence and management of asthma in the Sudan.

Questions:
1. The criteria used to include patients in the study are not clear that this doctor diagnosed or patient perceived. This is an important question because there are many other respiratory conditions that closely mimick but are not asthma such is fibrotic lung diseases. Could the authors clarify their inclusion criteriae.

2. The mixing of quantitative and qualitative analysis in one report although previously done, tends to belabor the points raised. There is repetitiveness of many statements, in some cases verbatim.

3. Tables 4 and 5 contain information that is extracted verbatim from the text. This makes the information repetitive.

4. The paragraphs "Health Policy level" and "Organisational and Health Systems" under Results do not appear to report the findings of the authors, these come out as recommendations and suggestions.

5. The authors could consider simple tables to capture the information where applicable, eg. under the paragraph diagnostic equipment, asthma drugs and health care provider training.

6. Strengths and limitations does not appear to address the strengths or limitations of the work being reported.

Is the work clearly and accurately presented and does it cite the current literature?
Partly

Is the study design appropriate and is the work technically sound?
Partly

Are sufficient details of methods and analysis provided to allow replication by others?
Yes

If applicable, is the statistical analysis and its interpretation appropriate?
Not applicable

Are all the source data underlying the results available to ensure full reproducibility?
Are the conclusions drawn adequately supported by the results?
Yes

**Competing Interests:** No competing interests were disclosed.

**Reviewer Expertise:** Asthma, Allergy and Clinical Immunology

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

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**Author Response 13 Jan 2021**

**rachael thomson,** Liverpool School of Tropical Medicine, Liverpool, UK

Thank you very much for taking time to review this article. Your comments are very appreciated and it is good that you see the importance of this issue.

We will go through and revise the article in line with your comments. We will aim to make the inclusion criteria much clearer. Apologies for any repetition in quotes, we will address this. We will also look at the text in the results section around health policy and organisations factors. Putting some of the data from the facility survey into a table is very helpful and we will also review the strengths and limitation section.

**Competing Interests:** No competing interests were disclosed.

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**Reviewer Report 28 October 2020**

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**Robin J. Green**
Department of Paediatrics and Child Health, University of Pretoria, Pretoria, South Africa

The basic error is no definition of asthma in the patients is given. What was there diagnosis based on? What severity of asthma and what medication were they using?

In addition it seems improbable to extrapolate conclusive findings from 14 patients.

I would not suggest publication in this journal as the article is not methodologically sound
Is the work clearly and accurately presented and does it cite the current literature?  
Yes

Is the study design appropriate and is the work technically sound?  
No

Are sufficient details of methods and analysis provided to allow replication by others?  
No

If applicable, is the statistical analysis and its interpretation appropriate?  
No

Are all the source data underlying the results available to ensure full reproducibility?  
No

Are the conclusions drawn adequately supported by the results?  
No

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Paediatric Pulmonology

I confirm that I have read this submission and believe that I have an appropriate level of expertise to state that I do not consider it to be of an acceptable scientific standard, for reasons outlined above.

Author Response 13 Jan 2021  
rachael thomson, Liverpool School of Tropical Medicine, Liverpool, UK

Thank you very much for taking the time to review this article. We appreciate your comments.

It would be helpful to understand a little more about your concern on the number of patients interviewed. This is the qualitative part of the study and 14 patients is a very standard number for qualitative research. The number chosen was based on whether saturation of results was found. The analysis for the qualitative component was using the thematic framework and the coding frameworks could be used by other qualitative researchers if they wanted to replicate the work.

The quantitative facility survey was much larger and the survey is available and therefore could be replicated if wanted.

The choice of a mixed methods study was so that the quantitative facility survey could describe what is available in terms of services while the qualitative component aimed to gain an in-depth understanding of the motivation of seeking care and how living with asthma affected them.
I hope this has clarified things a bit more for you.

**Competing Interests:** No competing interests were disclosed.

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