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THE ECONOMIC BURDEN OF MYCETOMA ON HOUSEHOLDS IN THE SUDAN

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ABSTRACT

Background: The fungal disease mycetoma, more commonly known as Madura foot after the Indian city where it was documented, enters the body through small cuts in the skin. Accurate data on the number of mycetoma patients in Sudan is difficult to obtain, in part because it is not a notifiable disease. Nevertheless, Mycetoma Research Centre (MRC) has registered over 7200 mycetoma cases in Sudan since 1991, so it is now a major public health problem with enormous cost burdens on the patients'. The study aims to assess the economic consequences or costs of mycetoma disease on patients in public hospitals in the Sudan, and provide the different classification of mycetoma costs that facing the patients, and explain to what extent mycetoma patients are able to cover this costs. **Methods:** This study is an exploratory study, the primary data are obtained from a questionnaire directed to a sample of patients treating from mycetoma in the Sudan, about 40 questionnaire were distributed to mycetoma patient's in public hospitals in Khartoum state and Gazira state during the period August 2015 to February 2016. **Results:** The study showed that mycetoma has a negative impact on youth, productivity and employment. The cost of diagnosis and treatment is relatively high, total costs for patients per week is ranged between 901 – 1100 SDG. These costs vary but the main source of costs are: treatment costs, X-ray, lab tests and different diagnosis costs, Transportation and meals costs, and other additional costs. Also there are indirect costs such as leaving the work after become sick. 90% of the respondents mentioned that their income is not enough to cover all the costs. As income not enough they are resort to having support from friends and relatives, acquisition and borrowing, and other options, so those who cannot afford treatment costs suffer disproportionately, and those who do pay for care are at risk of falling into poverty. As a result of high costs and un-ability to cover these cost, most patients stopped therapy, were lost to follow-up in outpatient clinics, and presented late with a massive relapse that often required amputation and more treatments which means increasing the costs.

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INTRODUCTION

Mycetoma is a chronic, progressively destructive morbid inflammatory disease usually of the foot but any part of the body can be affected. Infection is most probably acquired by traumatic inoculation of certain fungi or bacteria into the subcutaneous tissue. Mycetoma was described in the modern literature in 1694 but was first reported in the mid-19th century in the Indian town of Madura, and hence was initially called Madura foot. (WHO Report 2015). Mycetoma is considered since 2016 as a neglected disease by the World Health Organization (WHO), accurate data on its incidence and prevalence are not available and remains without any control program for prevention or surveillance. However, as in the case of Buruli Ulcer, early detection and treatment are important to reduce morbidity and improve treatment outcomes. The causative organisms of mycetoma are distributed worldwide but are endemic in tropical and subtropical areas in the 'Mycetoma belt', which includes the Bolivarian Republic of Venezuela, Chad, Ethiopia, India, Mauritania, Mexico, Senegal, Somalia, Sudan and Yemen (Ibid). Mycetoma commonly affects young adults, particularly males aged between 15 and 30 years, mostly in developing countries. People of low socioeconomic status and manual workers such as agriculturalists, labourers and herdsmen are the worst affected. Global burden is not known, but a 2013 survey reported a total of 8763 cases. www.who.int/

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mediacentre/factsheets/mycetoma/en/. Mycetoma is not a notifiable disease (a disease required by law to be reported) and no surveillance systems exist. There are no prevention or control programmes for mycetoma yet. Preventing infection is difficult, but people living in or travelling to endemic areas should be advised not to walk barefooted. On 28 May 2016, the 69th World Health Assembly approved a resolution (WHA 69.21) recognizing Mycetoma as a neglected tropical disease. Elaborating a public health strategy for the prevention and control of Mycetoma requires collection of epidemiological data on burden of disease, investment in research and product development, so that cost-effective prevention, diagnosis, early treatment and case management can be practised in low-resource settings. At present, active case-finding with early diagnosis and treatment with currently available tools is the most appropriate approach for lessening Mycetoma's disease burden (Ibid). Mycetoma has a worldwide but uneven distribution. The disease is endemic in tropical and subtropical regions but the African continent has the highest prevalence. Mycetoma prevails in the mycetoma belt that stretches between the latitudes of 15° south and 30° north of the equator. The belt includes Sudan, Somalia, Senegal, India, Yemen, Mexico, Venezuela, Columbia, Argentina, and other countries. In Africa, Sudan seems to be the homeland of the disease. (Fahal AH 2011, Fahal AH 2004,Fahal AH and Hassan MA 1992).

The Problem of the Study

Recently, numbers of published studies looking at the economic burden or impact of disease has dramatically risen. The increased demand for this type of information has been fuelled by the view among many public health officials that it might influence the decision of a ministries of finance or economics specifically in less developed countries which always suffered from insufficient of resource allocation in health, to release additional funds to combat a specific health problem or threat. WHO stated that Mycetoma has numerous adverse medical, health and socioeconomic impacts on patients, communities and health authorities, as it consumes a lot of resources and materials. The result is a high burden of costs on patients. As there are few review studies conducted to determine the cost of Mycetoma on patients in Sudan, the main problem of this study is to explain this matter so as to support health care planners, decision makers and other interested partners to make more decisions regarding cost minimization and to combat this health problem.

The Questions of the study

Although insufficient as a basis for resource allocation in health in less developed countries, appropriate estimation of the economic costs associated with a particular disease such as mycetoma can certainly contribute to or address a number of questions, such as:

- What are the economic impacts of diseases on the economies?
- What are the types of economic costs of diseases generally?
- What is the size and the spread of mycetoma in Sudan?
- What are the economic costs of mycetoma on patients in Sudan?
- What are the components of economic costs of mycetoma on patients in Sudan?
- How much of a household's income is reduced by the inability to work or is used up for medical care?
- Are patients income is enough to pay the costs, and what are the coping strategies used by patients to cover the costs?

The Objectives of the Study

The general objective of this study is to assess the economic consequences or costs of mycetoma disease on patients in public hospitals in the Sudan.

More specifically the objectives of this study are

- To explain the different types economic costs of mycetoma on patients in public hospitals in Sudan.
- To explain to what extent patients are able to pay this costs and what are the different alternatives for patients to cover this cost.

The Importance of the Study

The costs issues affect the ability of many consumers to access and use goods and services, so treating mycetoma may decrease when its costs are high. The study will help to provide a wide depiction of the costs of mycetoma on patients in Sudan to support health care planner, decision makers and other interested partners to make more decision regarding cost minimization and reducing the burden on patients. The reliable and accurate results of the research dealing with mycetoma costs are essential to give a massive knowledge gap in mycetoma and can be used to improve the patient's management and disease control.

MATERIALS AND METHODS

Methodology of the Study: The study is an exploratory study, the primary data will be obtained from a questionnaire that was prepared and distributed to a sample of patients' treating from mycetoma in the Sudan.

The Population of the Study: The population of this study is patients treating from mycetoma in the Sudan.

The Sample of the Study: Due to the size of the study, time and budget limitation, the sample of the study is about 40 mycetoma patient's in two public hospitals treating mycetoma cases in Khartoum state and Gazira state.

Method of data collection: The study will adopt a nonprobability purposive sampling method, following multi-stage.

Data Collection

Secondary data: Were obtained from references, journals, articles and websites.

Primary data: Were obtained from a questionnaire conducted with mycetoma patients.

Data collection tools: The study will utilize quantitative data that will be obtained using a questionnaire, about 40 questionnaire will be distributed to mycetoma patient's in

public hospitals in Khartoum state and Gazira state during the period August 2015 to February 2016.

Time Framework of the Study: Fulfilment of this study will be intended during the period from April 2016 to October 2016 in Khartoum State and Gazira state in the Sudan. Patients' data as well as cost details will be collected for a period of six months.

Literature Review

The number of economic impact studies in health has grown exponentially since the codification of a 'cost-of-illness' framework in the mid-1960s. Although most studies continue to use some variant of this methodology (which combines the 'direct' costs of medical care, travel costs etc. with the 'indirect' cost of lost production because of reduced working time), macroeconomic growth models have increasingly been used to better understand the dynamic and multifaceted nature of losses at the societal level. There has also been increasing policy and research interest in better understanding the microeconomic consequences of ill-health, particularly at the household level in lower-income countries (WHO, 2009). Looking across the large body of existing literature, it is apparent that there is a considerable degree of methodological heterogeneity, and also that many studies suffer from a range of conceptual deficiencies. Ill-health can contribute to losses in individual utility or social welfare in a number of defined ways, both directly (because people prefer to be more healthy than less healthy) and indirectly by reducing the enjoyment or utility associated with the consumption of goods and services unrelated to health, or by compromising other economic objectives such as producing income that allows people to consume market goods. Since the consumption of health goods and services in general does not yield utility or welfare directly - people would prefer not to incur these expenses in terms of money and time - the key direct determinants of economic welfare can be summarized as the consumption of non-health goods and services, leisure, and health itself. It is the impact of disease or injury on these domains of economic welfare that should form the basis of estimation (Ibid).

Mycetoma or Madura foot is a chronic, progressively destructive morbid inflammatory disease usually of the foot but any part of the body can be affected. Infection is most probably acquired by traumatic inoculation of certain fungi or bacteria into the subcutaneous tissue. Mycetoma was described in the modern literature in 1694 but was first reported in the mid-19th century in the Indian town of Madura, and hence was initially called Madura foot. Mycetoma commonly affects young adults, particularly males aged between 20 and 40 years, mostly in developing countries. People of low socioeconomic status and manual workers such as agriculturalists, labourers and herdsmen are the worst affected. Mycetoma has numerous adverse medical, health and socioeconomic impacts on patients, communities and health authorities. http://www.who.int/buruli/mycetoma/en/# Mycetoma transmission occurs when the causative organism enters the body through minor trauma or a penetrating injury, commonly thorn pricks. There is a clear relationship between mycetoma and individuals who walk barefooted and are manual workers. The disease is common among barefoot populations who live in rural areas in endemic regions but no person is exempted. http://www.who.int/mediacentre/ factsheets/mycetoma/en/ A major problem in mycetoma is that the most of the patients are of poor socio-economic and health education status and hence the late presentation, poor treatment compliance and high follow-up dropout rates. The lack of national and international attentiveness and awareness on the disease has led to a massive knowledge gap in mycetoma that had significantly and adversely affected patient care and management and proper planning for mycetoma preventative measures.(Fahal AH (2017) Mycetoma: A globalmedical and socio-economic dilemma. PLoSNeglTrop Dis 11(4): e0005509. https://doi.org/10.1371/journal. pntd.0005509. It is still challenging and hard to treat patients with mycetoma; in particular eumycetoma. The current treatment is still not optimal and disappointing. To cure, this disease both extensive and destructive surgery and prolonged antifungals treatment are necessary. With the current drugs, Ketoconazole and Itraconazole, improvement has been demonstrated, but cure rates for eumycetoma are still significantly lower than cure rates for action mycetoma. These drugs need an extended period to affect a partial cure, they have many side effects and contraindicated in during pregnancy and lactation. The prolonged use of the available drugs proved to be not cost effective for the health authorities and patients. Surgery is curative in early cases but the fact that patients present late made its outcome to be stigmatising due to the massive mutilating surgical excisions or amputation. A study from the Mycetoma Research Centre (MRC), Sudan, showed that of the 1242 patients with eumycetoma studied, only 321 (25.9%) were cured, 35 (2.8%) had amputations, and 54% dropped out from the outpatient follow-up. There were various reasons for the dropout but the important one was patient's dissatisfaction (Ibid).

Many researchers consider the Sudan as the mycetoma homeland. The first report on mycetoma was at the turn of the eighteenth century, and since then many documentation mycetoma have been reported. However, there is no recent report on mycetoma in the country. In1977 Mahgoub published data on mycetoma in Sudan, but no more data were published until the Mycetoma Research Centre (MRC) was established. Fahal and et al study reports in 2015 showed that, on 6,792 patients with mycetoma seen and managed at the MRC in a period of 23 years ;5,150 (76%) of them were males and 1,642 (24%) were females. Their age ranged between 3 and 88 years with median of 25 years (mean 29±0.2 standard error). Most of them, 4,353 (64%), were less than 30 years old at presentation, 1,586 (23%) were under 20years old and 2,435 (36%) were 30years old or more. In this study 1,872 (28%) students were affected. This was followed by farmers 1,239 (18%) and manual domestic workers 1,239 (18%). Due to the prolonged illness and disability, 628 (9%) patients were unemployed. Housewives constituted 13%of the patients. The study showed that, 2,476 patients (37%) were from Gezira State; 837 patients (12%) were from White Nile State and 747 patients (11%) were from North Kordofan State.

There was also a significant number of patients from the Capital, Khartoum State 1,037(15%). Darfur States were the least affected area. In this series, thirty three patients were from neighbouring countries of Chad, Ethiopia, Saudi Arabia, Eritrea and some were from Yemen. (Ahmed M. EL Hassan, Manar El sheikh, Fahal A, Mahgoub ES, Hassan AME, Abdel-Rahman ME, 2015). The estimated prevalence ranged from 3.49 cases per 100,000 inhabitants in Mauritania to <0.01 cases per 100,000 inhabitants in many other countries. The estimated prevalence for the endemic areas of mycetoma,

Mexico and Sudan, were 0.15 and 1.81 cases per 100,000 inhabitants (Van de Sande WWJ, Maghoub ES, Fahal AH, Goodfellow M, Welsh O, Zijlstra E, 2014). Surveys performed in mycetoma-endemic villages in Sudan suggest a prevalence ranging from 0–8.5 per 1,000 inhabitants. https://doi.org/10.1371/journal.pntd.0002667.t001. Fahal declared that in august 2016 MRC seen and managed about 7,537 patients with mycetoma, about 200 cases weekly and 300 new cases discovered annually. Fahal mentioned that the treatments are expensive and the cost may reach about 40 SDG per day for patient. Most of the patients cannot afford these costs of treatment. Furthermore, the drugs are not always available in endemic regions it need to travel to the centres where the drugs are available that leads to increase the costs of treatment. The treatment is of a variable duration and may continue for 3 years. Therefore, some patients may stop the treatments which lead to further complications then massive surgical excisions or amputation of the affected part is the choice available for treatment (Al Intebaha Newspaper, 11 August 2016).

Mycetomahas severe socioeconomic consequences: children drop out of school and their peer group, and young adults cannot finish their training or find ajobor a partner. Patients are affected psychologically because of the lack of health services, the physical disability, and the lack of prospects, as the outcome of treatment is poor and often leads to amputation of the affected part (Fahal AH, 2004). A study conducted at the Mycetoma Research Centre, Khartoum Sudan, in the period November 2012 to February 2013, showed that, a high prevalence of herbal treatment usage among the studied cohorts. The explanation of this is multifactorial, to mention but few, the patients poor socio-economical classes and health education and their dissatisfaction with the prolonged medical treatment, its many side effects and the high recurrent rate. The herbal treatment is characterized by wide availability, cultural acceptability, reasonable cost and the conception of safety among most patients.

This study demonstrated a perception of safety in more than half of herbal users and this may explain the high prevalence of herbal treatment among the study population. Many observations from the Sudan and from the current study showed that, this type of treatment is associated with many complications such as skin burn and necrosis, sepsis, septicaemia and it is an important cause for further local tissue damage and destruction, deformity and disability. It interesting to note that, many patients tend to deny these complications for various reasons (Eshraga A., Fahal AH, and Anjom O. 2013).

ANALYSIS AND RESULTS

Analysis of questionnaire

The study included 50 patients with confirmed mycetoma. Table 1, showed that (70%) of them were males and (30%) were females. Their age ranged between 10 and 80 years, most of them, (62%), were less than31 years old, (22%) were under 20years old and (38%) were above than 30 years old. (74%) of them were unemployed. Most of them has duration of mycetoma, from one year to 3 years (50%). The study showed that (26%) farmers were affected. This was followed by workers (18%) and students (18%). Housewives constituted 16%of the patients also Clarks and other jobs represented (6%) and (10%) respectively.

Table 1. Characteristics of the study patients

Variable		Number	Percentage
Gender	Male	35	70%
	Female	15	30%
	Less than 15	3	6%
	15 – 20	8	16%
Age distribution	21 – 30	20	40%
	31 – 50	13	26%
	Above 50 years	6	12%
Occupation	students	7	14%
	farmers	13	26%
	workers	5	10%
	Clarks	2	4%
	housewife	7	14%
	not working	2	4%
	Other jobs	5	10%
	Animal grazing	9	18%
	Less than I year	5	10%
Duration of	One to 3 years	25	50%
Mycetoma	4 to 7 years	14	28%
	More than 7 years	6	12%

Table 2. Income Per month

Items	Number	Percentage
Less than 450 SD	31	62%
450 - 700 SD	13	26%
701 - 1000 SD	2	4%
1001 – 2000 SD	2	4%
More than 2000 SD	2	4%
Total	50	100%

The majority of mycetoma patients are of low income groups as 88% of the patients income is 700 SDG per month and less. (62%) of patients have income less than 450 SDG per month while about 4% of patients have income more than 2000 SDG per month.*(Note: 1$ equal to 17.000 Sudanese pound (SDG) in July 2018 according to the official rate of the central bank of Sudan)*

Table 3. Visiting doctors cost per month

Items	Number	Percentage
100 - 300 SDG	17	34%
301 – 500 SDG	20	40%
501 – 700 SDG	4	8%
701 – 900 SDG	6	12%
More than 900 SDG	3	6%
Total	50	100%

Table 3. Showed that, (74%) of the respondents visiting doctors costs ranged between 100 – 500 SD per month. (40%) of them have visiting doctors costs about 301 – 500 SDG per month.

Table 4. Surgery costs

Items	Number	Percentage
Less than 500SDG	14	28%
501 -700 SDG	14	28%
701 – 900 SDG	2	4%
901 – 1100 SDG	3	6%
More than 1100 SDG	17	34%
Total	50	100%

Table 4. Showed that, the surgery costs vary depending on the size of the surgery. About 28% of the respondent's surgery costs is less than 500 SD, 28% of them costs is between 501-700 SD, and 34% of them costs is more than 1100 SDG.

Table 5. Treatment costs per week

Items	Number	Percentage
Less than 200 SDG	5	10%
200– 500 SDG	25	50%
501 - 800 SDG	10	20%
801 – 1100 SDG	5	10%
More than 1100 SDG	5	10%
Total	50	100%

Table 5, showed that, (50%) of the respondents mentioned that, their treatment costs per week ranged from 200 – 500 SDG.

Table 6. X-ray, lab tests and different diagnosis per week

Items	Number	Percentage
Less than 300 SDG	5	10%
300 - 500 SDG	25	50%
501- 700 SDG	8	16%
701 – 900 SDG	1	2%
901- 1100 SDG	5	10%
More than 1100 SDG	6	12%
Total	50	100%

Table 6, showed that, (50%) of the respondents mentioned that, their X-ray, lab tests and different diagnosis costs per week ranged from 300 – 500 SDG.

Table 7. Transportation and meals costs per week

Items	Number	Percentage
200-500 SDG	26	52%
501- 800 SDG	14	28%
801 – 1100 SDG	4	8%
More than 1100 SDG	6	12%
Total	50	100%

Table 7, showed that, (52%) of the respondents stated that, their transportation inside the city and meals costs per week ranged from 200 – 500 SDG.

Table 8. Do you leave work after become sick?

Items	Number	Percentage
Yes	35	70%
No	15	30%
Total	50	100%

Table 8, showed that, 70% of the respondents leave their work after become sick, that mean this disease is responsible for many people to be out of lobour force and not to be economically active.

Table 9. Monthly salary before leaving work

Items	Number	Percentage
Less than 450 SDG	7	14%
450-800 SDG	14	28%
801- 1200 SDG	8	16%
1201 – 2500 SDG	16	32%
More than 2500 SDG	5	10%
Total	50	100%

Table 9, showed that, people monthly salary before leaving work vary, but about 32% of the respondent's monthly salary before leaving work ranged between 1201-2500 SDG.

Table 10. Total costs per week

Items	Number	Percentage
Less than 500 SDG	8	16%
501-700 SDG	10	20%
701- 900 SDG	13	26%
901 - 1100 SDG	19	38%
Total	50	100%

Table 10, showed that, total costs for patients per week vary, but 38% of the respondents total cost ranged between 901 – 1100 SDG.

Table 11. Is there are other additional costs, please mention it

Items	Number	Percentage
Yes	7	%14
No	43	%86
Total	50	%100

Table 11, showed that, 86% of the respondents stated that there are other additional costs such as: additional treatments, food supplements, travel outside the state, additional meals, rent house beside the hospital, etc.

Table 12. Is income cover all costs?

Items	Number	Percentage
Yes	5	%10
No	45	%90
Total	50	%100

Table 12, showed that, 90% of the respondents mentioned that their income is not enough to cover all the costs while only 10% of them assumed that income cover all the costs.

Table 13. If income is not cover costs, what shall you do?

Items	agree	Percentage	disagree	percentage
Go to Zakat Chamber	19	%38	31	%62
Covering by Health Insurance	23	%46	27	%54
Covering by charity organizations	16	%32	34	%68
Relatives and friends support	39	%78	11	%22
Acquisition and borrowing	34	%68	16	%32
other	12	%24	38	%76

Table 13, showed that, there are many options that people resort to as income not enough to cover all costs such as: having support from friends and relatives(%78), acquisition and borrowing (%68), covering by health insurance (%46), zakat chamber (%38) and other option.

RESULTS

The study showed that (70%) of patients with confirmed mycetoma were males, (62%) were less than 31 years old, also (26%) who were affected were farmers, also workers, students, housewives and Clarks constituted a large percentage of patients so mycetoma has a negative impact on youth, productivity and employment. The cost of diagnosis and treatment is relatively high, total costs for patients per week as 38% of the respondents stated is ranged between 901 – 1100 SDG. These costs vary but the main source of costs are: treatment costs, X-ray, lab tests and different diagnosis costs, Transportation and meals costs, and other additional costs. Also there are indirect costs such as leaving the work after become sick as 70% of the respondents become without work due to their sickness. 90% of the respondents mentioned that their income is not enough to cover all the costs. there are many options that people resort to as income not enough to cover all costs such as: having support from friends and relatives (%78), acquisition and borrowing (%68), covering by health insurance (%46), zakat chamber (%38) and other options, so those who cannot afford treatment costs suffer

disproportionately, and those who do pay for care are at risk of falling into poverty. As a result of high costs and un-ability to cover these cost, most patients stopped therapy, were lost to follow-up in outpatient clinics, and presented late with a massive relapse that often required amputation and more treatments which means increasing the costs.

Conclusion

This study demonstrated that the costs of mycetoma on households in public hospitals in less developed country remained high, and have many complications as patient's income is not enough to cover these costs. However, mycetoma has a negative impact on youth, productivity and employment and still places a significant burden on the people of less developed countries as they are at a risk of falling into poverty. Whilst possibility of further cost reduction exists by more efforts by Ministries of Health, WHO, and International Organizations to strengthening health system and capacity building, monitoring and evaluation, research, advocacy, and prevention. As mycetoma is a neglected disease, reduction of costs should be by making accurate data on its incidence and prevalence are available. Resource mobilization is necessary to support public hospitals for providing early detection and treatment at low costs, are important to reduce morbidity and improve treatment outcomes.

List of Abbreviations

WHO: World Health Organization
MCR: Mycetoma Research Centre
WHA: World Health Assembly
SDG: Sudanese Pound

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Appendix 1

Questionnaire Guide:

1. Characteristics of the study patients: Gender, Age distribution, Occupation, Duration of Mycetoma.
2. Income Per month.
3. Visiting doctors cost per month.
4. Surgery costs.
5. Treatment costs per week.
6. X-ray, lab tests and different diagnosis per week.
7. Transportation and meals costs per week.
8. Do you leave work after become sick?
9. Monthly salary before leaving work
10. Total costs per week.
11. Is there are other additional costs, please mention it.
12. Is income cover all costs?
13. If income is not cover costs, what shall you do?

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