

The Mycetoma Research Centre experience during the COVID-19 pandemic: obstacles and beyond

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Received 26 February 2021; revised 23 May 2021; editorial decision 1 July 2021; accepted 14 July 2021

Keywords: COVID-19, mycetoma, pandemic, patient, Sudan

Mr E. L. Safi is a middle-aged singer and musician from West Sudan. He is representative of the large number of patients who experienced long-standing mycetoma during the COVID-19 pandemic, along with their families, the medical, health and socioeconomic community and the health system at large. The patient had mycetoma that eventually ended in leg amputation due to neglect of the small, painless subcutaneous swelling of his foot, resulting from his low socioeconomic and health education levels, geographical isolation, as well as the disruption to medical care caused by the impact of the COVID-19 pandemic.

The COVID-19 pandemic

Coronavirus disease 2019 (COVID-19) is a major health problem worldwide and almost every country affected by the disease has experienced a high mortality rate. It has caused 2 460 000 deaths worldwide over a period of 14 mo. In Sudan, the virus affected 34 889 individuals, of whom 27 949 recovered, while 2568 deaths occurred.¹ The COVID-19 pandemic led to reorganisation of healthcare facilities, many of which were closed, along with a lack of operational medical staff, fully equipped facilities and personal protective equipment.^{1,2} In this communication, we reflect on our experience at the Mycetoma Research Centre (MRC), University of Khartoum—a WHO Collaborating Centre—where abrupt interruption to services at national level due to the pandemic had a severe impact on clinical services and staff.

Mycetoma

Mycetoma is a neglected tropical disease (NTD) that is endemic in tropical and subtropical regions. Sudan has the highest disease burden.^{3,4} Mycetoma is a chronic granulomatous inflammatory disease caused by more than 70 microorganisms of bacterial and fungal origins. It is characterised by painless subcutaneous

masses that gradually increase in size, eventually developing multiple sinuses, which produce a purulent and seropurulent discharge that contains grains of different colours, sizes and consistency.⁵ The inflammatory process usually spreads to affect the skin, deep tissues, structures and bones, leading to massive tissue damage, destruction, deformity and disability, and it can be fatal if not treated properly in a timely fashion. The disease frequently affects young adults and children, creating massive socioeconomic constraints, education dropout and increased poverty and stigma.⁶ Patients usually present late with advanced disease. The reason for this is multifactorial, consisting of patients' low socioeconomic status, poor health education, a scarcity of health and medical facilities in endemic regions, reliance on traditional medicines, as well as geographical barriers, particularly during the rainy seasons.⁷ The current diagnostic tools and treatment options are limited and suboptimal, and the patient remains infected for a long time, if not for life.⁶ To respond to the difficulties facing patients, the MRC was established.⁷

The MRC, University of Khartoum

The MRC was established under the umbrella of the University of Khartoum in 1991. Currently, the MRC is recognised globally as a world leader in mycetoma management and research. It is a WHO Collaborating Centre on Mycetoma. More than 9500 mycetoma patients are registered with the MRC; most are seen regularly for treatment and follow-up. All the services at the MRC are provided free of charge. The MRC has two outreach mycetoma units to provide care and support for patients in endemic regions.³ To engage the community in disease prevention and control, the MRC approached different civil society groups in both Sudan and globally to raise and promote mycetoma advocacy for early case detection and management, as currently there are no reliable data upon which to base robust disease preventive and control measures.



Figure 1. Patients waiting to receive their medication at the MRC during the COVID-19 pandemic.

Effects of the prolonged national lockdown on the community and the economy

In a country like Sudan, where most of the population's income is dependent on day-to-day labour, the prolonged lockdown and closure of bridges and highways between cities resulted in a vast economic burden on many families, as well as on trade and businesses.¹ If needed, visits to hospitals cost twice as much compared with before the pandemic, and it was difficult to find suitable means of transport for the mycetoma patients affected.

Work quality and follow-up for mycetoma patients

The MRC has been serving a huge number of patients from various Sudan states and overseas, providing them with free diagnosis, medications, follow-up and other multidisciplinary services (Figure 1). It is worth mentioning that most of the mycetoma patients presenting to the MRC, like other NTD patients, are from low socioeconomic backgrounds and are largely illiterate. Since the lockdown started, the quality of services has notably reduced, despite all attempts to prevent this. Sadly, this was attributed to patient and staff safety measures and infection control policies set by the hospital in the patients' best interests. However, this has negatively affected their treatment and follow-up courses. This is exemplified in the failure to effectively run weekly follow-up clinics, during which 200 patients are usually seen. This could have been a result of patients being unable to attend the clinics due to travel restrictions, or because of prohibitively high transport costs when attempting to seek urgent medical help, or an inability to be seen by doctors who were only allowed to see new patients, review blood tests and prescribe medications through the pharmacy because of hospital policies regarding the treatment of non-urgent patients and the safety measures in place. This made the patients agitated, anxious and stressed, as they need timely and regular visits to decide on their treatment plans and interventions, which are dependent on individual assessment. Furthermore, they require frequent reassurance and support during their long-term management. During the COVID-19 pandemic, all non-urgent surgical operations were cancelled. This

seriously affected mycetoma patients: lesions started to increase in size, and secondary bacterial infections developed, leading to more tissue destruction and less response to medical treatment. Eventually, in some cases, the patient may have to undergo amputation. Moreover, the international travel ban and airport closure due to COVID-19 prevented many overseas patients from arriving at the MRC to receive proper assessment and management. Currently, 58 mycetoma patients from different countries, including Yemen, Saudi Arabia, Egypt, Somalia, Ethiopia, Chad and Bangladesh, are managed at the MRC.

Medical treatment difficulties

The major problem faced by patients was an inability to reach the MRC to receive medical treatment. This can be attributed to the blockage of bridges and highways and prolonged curfews. All the obstacles reported in this communication have significantly contributed to increasing patients' distress, financial burdens, interruption to treatment and a higher rate of complications, including secondary bacterial infection.

Effects of the pandemic on staff

A number of MRC staff were infected, despite strict infection control measures. The number of medical staff working was severely reduced as some were quarantined or were volunteering in COVID-19 emergency rooms, which also experienced severe staff shortages. Training programmes, weekly scientific meetings and journal clubs, which kept doctors up to date and strengthened evidence-based practice, were postponed. PhD student training and supervision were also affected, including overseas training. Various research projects were halted, affecting the staff's continuous professional development.

Interruption to awareness and advocacy campaigns

Working from home was an inefficient method with which to cover many of the MRC's tasks, including direct patient interaction, counselling, immediate interventions and missions to endemic areas. The MRC relies on regular outreach medical missions to endemic areas to raise disease awareness through health education sessions and advocacy for various preventive measures to the local communities. All these activities stopped during the pandemic. Moreover, these missions usually provide free-of-charge diagnosis and treatment for villagers in mycetoma-endemic regions and socioeconomic support in the form of free prosthesis and shoe donation.⁸

In conclusion, the COVID-19 pandemic seriously affected the management of mycetoma patients, the MRC's activities, disease awareness and advocacy at the community level. Many research and collaborative projects were interrupted. All these

factors severely increased the neglect of an already neglected tropical disease.

Authors' contributions: LAF, ESA, SMB, EES and AHF conceived the report; LAF, ESA, SMB, EES and AHF carried out the study; LAF, ESA, SMB, EES and AHF wrote the manuscript. LAF, ESA, SMB, EES and AHF revised the manuscript. All the authors read and approved the final version of the manuscript.

Funding: Not applicable.

Competing interests: The authors declare that they have no conflicts of interest.

Ethical approval: The study obtained ethical clearance from the MRC Institution Review Board.

Data availability: Data are available upon request.

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