SOCIO-CULTURAL AND POLICY SITUATION OF MYCETOMA AND ITS MANAGEMENT IN SUDAN: A CRITICAL EXPLORATION

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Declaration

I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is the original work of the author. The thesis has not been previously submitted to this or any other university for a degree and does not incorporate any material already submitted for a degree.

Abstract

Mycetoma is a chronic, granulomatous, devastating, and neglected disease occurring in tropical and subtropical regions. Sudan has recorded the highest number of mycetoma patients in the world, and has high poverty rates and an increasingly young age distribution, yet little is known about the social, political, and cultural aspects of the disease in the country. This thesis is the first study exploring mycetoma disease in Sudan using qualitative methods. It presents an in-depth analysis of the disease through the lenses of critical medical anthropology theory.

By adopting a qualitative ethnographic approach, the study uncovers the intricate power dynamics among diverse stakeholders at different levels, influencing the management of mycetoma and shaping the experiences of those affected. Through the inclusion of key Sudanese actors, such as individuals with mycetoma, carers, traditional healers, community members, healthcare providers, policymakers, and researchers, a holistic understanding of the disease's sociocultural and policy contexts is achieved.

Drawing from empirical data and ethnographic insights, the thesis first highlights the lived experiences of individuals affected by mycetoma, revealing the multifaceted impact of the disease on their livelihoods and social integration. I show how individuals with mycetoma simultaneously suffer from different forms of stigma – felt, enacted, and institutionalised – and I illustrate the different sources of stigma: from caregivers, families, community, and even healthcare providers.

The thesis also explores the failures of a global health intervention, that of the artificial animal enclosure, and through this example I emphasise the importance of understanding local communities' views of healthcare initiatives, and argue that a culturally sensitive approach to planning interventions and policies is essential to ensuring their effectiveness and sustainability. The thesis then delves into medical pluralism dynamics and their implications for mycetoma management, recognising traditional healers as key healthcare providers in the local context and underscoring the importance of incorporating their knowledge into health strategies. I identify new treatment pathways, cultural concepts, and beliefs in mycetoma management.

In exploring these issues, in this thesis I explore the politics of mycetoma management, and place mycetoma within the broader policy context, analysing existing national policies, strategies, and guidelines related to the disease's management in Sudan. The role of the

Mycetoma Research Center (MRC) as a dominant player in the field is scrutinised, and the power dynamics that influence the implementation of mycetoma-related policies are explored. Through this exploration, I contend that a comprehensive response to mycetoma necessitates addressing power imbalances and engaging various stakeholders, including the Federal Ministry of Health, in coordinated efforts.

By illuminating the social, cultural, and policy climates surrounding mycetoma disease, this thesis emphasises the need for stigma reduction strategies, the importance of addressing power imbalances within the policy landscape, and the potential for collaboration between traditional and modern healthcare providers to improve mycetoma care in Sudan, hoping to assist the development of evidence-based prevention and response interventions that are inclusive, culturally sensitive, and contextually appropriate.

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Dedication

I dedicate this work to my family and my many friends. My heart is filled with a deep sense of gratitude towards my loving parents, who have always encouraged me and instilled in me the value of perseverance. This dedication also extends to my grandmother Arfa, my uncles and aunt, as well as my brothers Ibrahim, Awab, Braa, and Monib, and to my exceptional sister Esra. Their unwavering support and love have been the foundation of my journey.

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List of Abbreviations

AIDS: Acquired Immune Deficiency Syndrome.

APOC: African Programme for Onchocerciasis Control.

BSMS: Brighton and Sussex Medical School.

BU: Buruli Ulcer.

CNCDC: Communicable and Non-Communicable Disease Control Department.

CVDs: Cardiovascular Diseases.

DALYs: Disability-Adjusted Life-Years.

DM: Diabetes Mellitus.

DNDi: Drugs for Neglected Diseases Initiative.

ESRI: Environmental Systems Research Institute.

FINIS: Framework Integrating Normative Influences on Stigma.

FMOH: (Sudanese) Federal Ministry of Health.

GDP: Gross Domestic Product.

GAVI: Global Alliance for Vaccines and Immunizations.

GMWG: Global Mycetoma Working Group.

HRH: Human Resources for Health.

HAT: Human African Trypanosomiasis.

HIS: Health Information System.

HIV: Human Immunodeficiency Virus.

JICA: Japanese International Cooperation Agency.

MAM: Mass Administration of Medicines.

MDG: Millenium Developmental Goal.

MRC: Mycetoma Research Center.

MRI: Magnetic Resonance Imaging**.**

NCD: Non-Communicable Diseases.

NGO: Non-Governmental Organisation.

NTD: Neglected Tropical Disease.

SCAR: Soba Center for Research and Audit.

SDG: Sustainable Development Goal.

SMOH: (Sudanese) State Ministry of Health.

STAG: Strategic and Technical Advisory Group.

PHC: Primary Health Care.

QGIS: Quantum Geographic Information System.

RGEC: Research Governance and Ethics Committee.

UK: United Kingdom.

UNDP: United Nations Development Programme.

USA: United States of America.

WHA: World Health Assembly.

WHO: World Health Organization.

Chapter One

Introduction

Chapter One: Introduction

Introducing Ahmed: the story of a person, not the disease

> My friend asked me why I did not marry again after my late wife died. I told him no woman would agree to marry an amputee. He insisted I marry his daughter. He went home and told her that my leg was amputated due to an ‘evil eye’ and lied to her about me being a strong army officer who lost his leg fighting. But then we talked, I told her the story [about mycetoma], I told her that I couldn’t guarantee bread on the table every day. She said ‘yes’ and said she agreed to whatever her father thought was right or not; we have a son now.

(Ahmed; a 39-year-old adult diagnosed with mycetoma)

Ahmed, a modest shopkeeper from the small Sudanese village of Wad Elnimear, struggles with mycetoma, a chronic, debilitating disease that affects not only his physical health but also his social interactions and emotional wellbeing. As I approached him for the first time in his shop, I could sense his apprehension and caution. He was lying down in his small bed in front of his humble market shop. When he noticed my presence, he assumed I was a customer interested in purchasing something from his shop. With deliberate movements, Ahmed retrieved his artificial leg from beneath the bed and slowly attached it without any assistance. Understanding the potential discomfort Ahmed might feel, I maintained a respectful distance and simply purchased a small pack of biscuits before quietly departing. However, being familiar with the village and its close-knit community, Ahmed quickly recognised me as an outsider, deducing that I was a researcher from the renowned Mycetoma Research Center (MRC). It was evident that he had encountered researchers before, as there had been previous ‘missions’ conducted in the village. Coincidentally, during that period, another medical mission organised by the MRC was underway in Wad Elnimear, Wad Onsa, and most of the eastern part of Sinnar State. The team was conducting surveys and engaging with the community members to gather valuable data and insights.

As days turned into weeks, Ahmed and I developed a unique bond, and he became my guide to the world of mycetoma. Through our conversations, I began to grasp the intricate web of social, cultural, and power effects that mycetoma and the health system imposed upon individuals. Ahmed’s struggles were not limited to physical impairments; they extended far beyond, infiltrating every facet of his existence. The impact of mycetoma on his educational opportunities, job prospects, and overall self-esteem was profound. It became increasingly clear that addressing mycetoma necessitated a holistic approach, one that encompassed medical, social, and psychological support.

Ahmed's resilience inspired me to amplify the voices of mycetoma patients and raise global awareness about the disease. Through sharing stories like Ahmed's, I hoped to break the stigma associated with mycetoma and ensure nobody had to face the condition alone. This journey initiated a commitment to highlighting mycetoma's multifaceted impact, advocating for better policies, and promoting collaborations to lessen the burden on those afflicted by this disease. Ahmed's experience illuminated that mycetoma is not just a medical condition; it's a complex issue entangled with people's livelihoods, social relations, and societal adaptations.

Figure 1: Ahmed's broken prosthetic leg fixed with a traditional rope.

A man meets mycetoma

As a young man in his thirties, Ahmed's journey with mycetoma began at the tender age of eight when a small lump appeared on the dorsum of his foot. Growing up in Wad Elnimear, Ahmed's family consisted of three siblings. Although his two brothers had migrated to other regions in search of employment opportunities, they too were affected by mycetoma. One of his brothers had undergone a below-knee amputation, while the severity of the condition was comparatively less for the other brother. Consequently, Ahmed had assumed a greater share of the financial responsibilities within the family unit.

Ahmed’s experience illustrates the profound impacts of mycetoma on an individual’s economic stability, with disease-associated stigma adding another layer of hardship. Those affected face social exclusion, discrimination, and limited opportunities due to cultural misconceptions and fears. Ahmed’s story underscores the need for comprehensive responses to mycetoma that address not only the medical but also the social and economic aspects of the disease. This involves implementing strategies to combat stigma and fostering economic empowerment for those affected, and requires a collaborative effort from government bodies, healthcare providers, community leaders, and the patients themselves.

As a medical anthropologist immersed in this profound journey alongside Ahmed and others like him, I am driven by a deep commitment to bring about positive change. By elevating their lived experiences, shedding light on the complex realities they face, and advocating for their rights, I can help to pave the way for a more inclusive and compassionate society.

> The doctor in Madani immediately ordered an X-ray for my leg, we did it. And when it came back, he found the mycetoma had already reached the bone and affected it. He tried to reassure me, and told me to come next week to do some debridement; I refused, I told him this is my foot, and I will know if it’s good or not. And I know it’s not well. I also told him I would not be able to hold all this pain, restlessness, and inability to sleep until next week. The doctor then asked me about my opinion, and I told him to amputate the leg. He refused at the start and said to me that I’m still a young chap and [if] we believe in God it will become better after the debridement. But I insisted and told him if you want to make me better, just amputee it. When the doctor saw my determination, he sent me to the yard. I was with both of my brothers and did not accept that I was not taking the doctor’s opinion and that I was the one who needed this amputation.

(Ahmed; a 39-year-old adult diagnosed with mycetoma)

Ahmed’s journey through the mycetoma healthcare system began with a traditional healer who performed a surgical procedure to remove the lump on his foot. Despite initial relief, the wound returned after two-and-a-half years. Determined, Ahmed sought professional medical help, experiencing several unsuccessful interventions and a period he described as a “nightmare”. He then turned to a doctor at Madani Hospital, where he decided to have his leg amputated; he faced resistance from the doctor, who eventually agreed. Ahmed’s narrative helps to highlight the importance of understanding healthcare-seeking pathways in medical anthropology, and sheds light on the complex realities faced by mycetoma patients in Sudan.

Ahmed’s story provides valuable insights into the power dynamics between the two prevailing systems for managing the implications of accessing effective treatment and living with the social and physical repercussions of the disease. Despite undergoing multiple surgeries, Ahmed found that his condition did not improve, leading him to seek advice from a traditional healer. His experiences highlight the potential role that traditional healing practices can play in conjunction with modern medicine. They also underscore the importance of having access to accurate information for making informed healthcare decisions.

Ahmed’s experiences also highlight the physical and emotional pain endured by mycetoma patients, suggesting a need for holistic approaches to understanding mycetoma management. Despite these struggles, Ahmed demonstrated resilience and resourcefulness, adapting his environment to fit his needs as an amputee. This showcases the need for greater consideration of accessibility and inclusivity for individuals with disabilities in all aspects of society.

In addition, Ahmed’s feelings of shame surrounding his prosthetic leg provide insight into the societal stigma and internalised shame associated with physical disabilities. This highlights the need for broader societal understanding, empathy, and reform to challenge such prejudices and misconceptions. Understanding these systemic and cultural complexities is crucial for devising comprehensive strategies to improve life for individuals living with conditions such as mycetoma.

Figure 2: Ahmed’s prosthetic leg in front of the mosque in Wad Elnimear village.

> “The distance to the front rows is too far”, was his response, and it is difficult for him to go all of the way inside the mosque. Although this was his initial answer, I couldn’t help but wonder if there was more to the story. I had seen Ahmed walk from his shop to the mosque for over 1 kilometre, so why did he hesitate to go the extra 20 metres to the frontline of this sacred space? He was clearly capable, but also uncomfortable about going “all the way in”.

(My fieldnotes, Wad Elnimear, Jun 2021)

One afternoon, I accompanied Ahmed to the local mosque as he attended the afternoon prayers. As I observed his participating in the religious rituals, I could not help but notice certain behaviours and actions that shed light on the depth of his emotional struggle. It became apparent that Ahmed’s shame regarding his prosthetic leg played a significant role in his interactions within the community. As Ahmed walked into the mosque, he would make subtle attempts to conceal his prosthetic leg, often wearing long, loose garments that concealed his limb as much as possible. His movements were cautious, and he seemed keenly aware of any glances or stares that might come his way. It was evident that he felt a strong desire to avoid drawing attention to his physical condition, perhaps fearing judgement or pity from others.

Ahmed’s reluctance to venture deep into the mosque, despite his physical capability, hinted at a deeper issue – a sense of shame rooted in societal and cultural norms regarding physical disabilities. As a medical anthropologist, I sought to understand the source and impact of these ingrained beliefs on individuals like Ahmed, who struggle with their physical differences. These cultural norms and societal expectations can lead to self-isolation, impacting social interactions and creating a cycle of marginalisation.

I recognised that this issue called for a comprehensive approach that would address societal perceptions of individuals with mycetoma, along with the systemic factors that reinforce stigma and limit opportunities. In Chapter Two, I outline my use of different methodologies to explore this issue further.

The Republic of Sudan

Ahmed lived in the Republic of the Sudan, a middle-income country located in Northeast Africa. Until July 2011, Sudan was the largest country in Africa, after which the south of Sudan seceded, resulting in Sudan’s division into two separate states, Sudan and South Sudan, following a peace agreement signed in 2005. However, this separation has not brought about lasting peace, as conflicts continue to arise between the two countries over the control of the town of Abyei. The disputed region, known for its oil reserves, remains a source of tension along the border (Ali et al., 2013). Amid the prolonged civil conflicts and wars, Sudan’s economy has suffered, and as a result, so have the country’s healthcare services. Sudan is currently the third-largest country in Africa; it occupies 1,886,068 km^2 and borders seven countries: Egypt, Libya, Chad, the Central African Republic, South Sudan, Ethiopia, and Eretria, as well as the Red Sea (Arowolo & Ali Biely, 2012; FMOH, 2012). The country has ten component states (Arowolo & Ali Biely, 2012; FMOH, 2012).

In the decentralised system, Sudan formerly consisted of 15 states. In 2013, this number increased to 18 states, after Darfur was divided into five states instead of three, and Kordofan into three rather than two states. Each state has some form of relative autonomy, as each has its own legislative council; however, many states rely on annual subsidies from the federal government. The population is also unevenly distributed across the 18 states (World Population Review, 2022). Figure 3 explains the population density, and shows how the population is unequally distributed within the capital state of Khartoum and close to water surfaces (rivers, lakes, and the Red Sea). The total population in 2012 was 35,055,538, with an annual growth rate of 2.5%, and an average fertility rate of 5.9%. The World Bank's 2020 estimation of the population was around 42.8 million, with a male to female ratio of 1:1 (The World Bank, 2022). Life expectancy is 63.4 for men and 66.5 years for women (Health & Central Bureau of Statistics, 2011), compared with 71 and 75 years being the average life expectancy for men and women consequently**.** The World Bank has classified Sudan as a low-income country (The World Bank, 2024). Sudan is a multicultural country where Arabic is the dominant language in contemporary country.

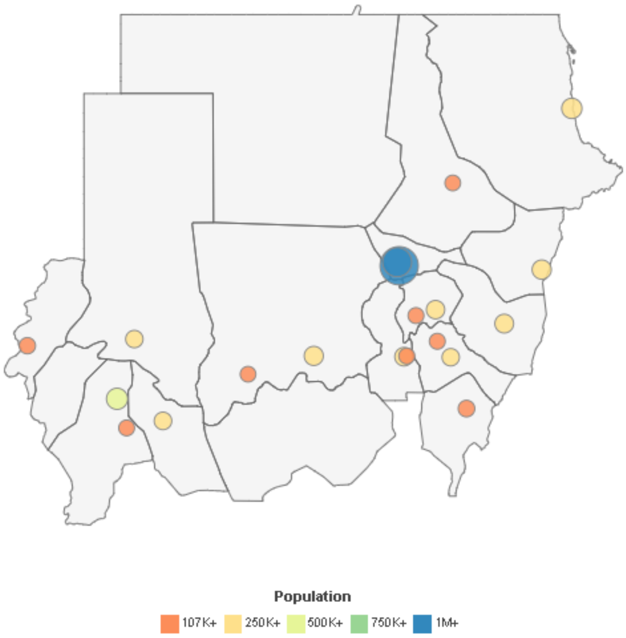

Figure 3: Population density across different states in Sudan (World Population Review, 2022).

The recent economic and political situation

The secession of South Sudan brought several economic shocks, with the oil revenue loss being the most substantial; this had previously accounted for more than half of Sudan's government revenue, and 95 per cent of its exports. These figures indicate that the split was economically to the advantage of South Sudan (Medani, 2011). This reduction in economic growth resulted in double-digit consumer price inflation and a fuel shortage, which, together with increased fuel prices, triggered violent protests in 2013, 2016, and 2018 (Hassan & Kodouda, 2019). There was also a shortage in the supply of foreign currencies such as US dollars, which resulted in a severe drop in the gross domestic product (GDP) and a remarkable devaluation of the currency; for example, the US dollar exchange rate increased from 2 SDG in 2010 to 7 SDG in 2013. The exchange rate of the US dollar in 2022 was estimated at 439 SDG. The deterioration in the value of Sudanese currency resulted in dissatisfaction among civil servants, and large numbers of highly skilled personnel started to migrate outside the country (Arowolo & Ali Biely, 2012). Included in these segments of new migrants to countries such as Saudi Arabia and other gulf countries, are university staff and health professionals, including doctors and other highly skilled health workers. In addition, there are around 3,000 Sudanese doctors working in the UK and the Republic of Ireland (FMOH, 2012). Additionally to this, the 2018 protests also resulted in a revolution, which ultimately led to Sudan's ex-president Omar al-Bashir being overthrown. The political landscape of Sudan is characterised by political instability and the frequent military coup d'états of presidents, the most recent of which occurred on 25 October 2021, when the Sudanese army deposed the transitional government (the seventeenth such event in Sudan since its independence in 1956; see Osman, 2021). Between April 2019 and October 2021, Sudan was governed by a transitional cabinet and a transitional sovereignty council. The United States designated Sudan as a state sponsor of terrorism in 1993, and diplomatic ties between Sudan and several other countries remained tense for almost three decades under the rule of Omar al-Bashir. Subsequently, Sudan was subjected to a trade embargo, which further weakened the economic state of the country. The sanctions of the US government were partly lifted in 2020 (*The Washington Post*, 2022).

On 15 April 2023, clashes occurred in urban areas, particularly in the capital city of Khartoum and the Darfur region. According to available information as of 20 June 2023, the conflict had resulted in an estimated death toll of 3,000 to 5,000 individuals, with an additional 6,000 to 8,000 people sustaining injuries. Moreover, by July 2023, approximately 2.2 million individuals were displaced within Sudan, while 645,000 others had sought refuge in neighbouring countries.

The conflict's inception involved the paramilitary Rapid Support Forces (RSF) launching attacks on government installations. Reports indicated the use of airstrikes, artillery, and small arms fire throughout Sudan. Mohammed Hamdan 'Hemedti' Dagalo, the leader of the RSF, and Abdel Fattah al-Burhan, Sudan's de facto leader and army chief, have been engaged in a power struggle, disputing control over various government sites, including the general military headquarters, the Presidential Palace, Khartoum International Airport, Burhan's official residence, and the headquarters of the Sudanese National Broadcasting Corporation (SNBC)

(El-Sadig et al., 2023). The data used in this research was collected and analysed before the outbreak of this most recent conflict.

The sociocultural dimensions of mycetoma

Mycetoma is endemic in the tropics, with existing literature indicating that Sudan, Mexico, and India bear the highest burden of the disease globally (Emery & Denning, 2020; van de Sande, 2013; van de Sande et al., 2014a). The chronicity of the illness has been well documented along with its treatment, diagnosis, and the difficulties in its management (see, for instance, Emmanuel et al., 2018a and Bakhiet et al., 2018). However, very little is known about the social and cultural dimensions of the disease and their implications for the mycetoma response. This thesis sheds light on the social determinants and consequences of the disease in rural Sudan, with particular attention to individual experiences of the illness and its wider impact on communities and healthcare providers.

This research is necessary to bridge the gap between the clinical narrative and person-centred realities surrounding mycetoma. The sociocultural and community-level disadvantages triggered by mycetoma must be deliberately documented to inform more effective public-health policies that address patient wellbeing beyond – but also fully including – management in hospitals and health facilities. This study, therefore, considers multi-stakeholder assessments across numerous settings, capturing missed perspectives and narratives from district to national levels. In so doing I hope that this research may serve as the potential starting ground for any upcoming intervention dealing with the disease of mycetoma, or with similar NTDs and will assist in moving towards a socially and culturally sensitive intervention. It will also provide a guide for designing a prevention plan for mycetoma, while considering the involvement of different levels of both policymakers and decision makers.

Research question

How do power relations affect the experience and management of mycetoma disease in Sudan?

Research objectives

1. Identify existing healthcare systems for mycetoma in Sudan and analyse the power dynamics and relationships between them.
2. Examine the stigmatisation associated with mycetoma disease.

3. Investigate the factors contributing to the unsuccessful implementation of the artificial animal enclosure project.
4. Evaluate the conceptualisation of mycetoma and its management by national-level policymakers in Sudan.

Thesis outline

In this thesis, I critically interrogate the social, cultural, and policy climates surrounding mycetoma in Sudan, grounding the investigation in critical medical anthropology theory in addition to social epidemiology theory, acknowledging the overlaps in the public health and social science dimensions around this illness. I explore the ways in which mycetoma disease and its management are affected by complex power dynamics between various stakeholders at different levels, and examine how, in turn, the experience of having mycetoma can be shaped by this power asymmetry. In order to understand the complex social dynamics around mycetoma, I adopted a qualitative ethnographic approach. The perspectives of the key Sudanese actors are considered: from individuals with mycetoma and their carers to traditional healers; from community members and healthcare providers to policymakers and researchers. In so doing, the thesis captures the experience of the individuals who encounter and seek to manage mycetoma in their daily lives. This approach helps to build a critical understanding of the sociocultural and policy situation of mycetoma and an emic understanding of the power dynamic of various players, contributing to highlighting the need for mycetoma prevention and response plans that are more inclusive, culturally sensitive, context-appropriate, and evidence-based.

In the first chapter, I introduce Ahmed’s story, that of a young Sudanese adult with disabling mycetoma. I explain Ahmed’s disease journey, of over 20 years. Following this, the mycetoma disease is introduced from a biomedical point of view, including its types, management, and pathophysiology. The reasons why mycetoma was chosen and why at this particular time are also denoted. The objectives, existing gaps, and intent to bridge them through the research are introduced, along with a highlighting of the economy and politics in Sudan.

The second chapter carefully explains the methodological approach used in this thesis. The chapter explains the methods used for data collection and analysis, including the study design and logical framework. The methods were tailored for Sudan’s mycetoma response and account for the many governmental, cultural, and social actors who navigate the mycetoma response. They also take great regard to the commonly ‘unheard’ and unrepresented local knowledge that is often trapped within rural communities and integrated into their culture; this has been actively sought out and included throughout this study, with purposeful inclusion of the critical actors at national, state, district, and community levels. Further, a description of each phase of the study is recounted, acknowledging the ethical considerations and challenges presented. I ground the emerging and existing literature in an anthropological lens, building up from acknowledging the ‘interpreter’ of the knowledge and my positionality and setting out the grounds for the ethnographic analysis that follows in the subsequent section. As a Sudanese medical professional, pre-exposed to different dimensions of the Sudanese community, and with in-built ‘tags’, mannerisms, and features assigned by my community, it is essential to acknowledge the person I am in relation to this study and its outcomes. While Sudanese, I am not a resident of the village of focus, nor am I closely linked to mycetoma or to an affected person. As a researcher, this added a level of complexity, as I was simultaneously an insider and an outsider. The last section in Chapter Two elaborates on my identity and positionality, further recognising how my distinctiveness can be understood or interrogated by the stakeholders included in this study.

In the third chapter I present the subject of neglected tropical diseases (NTDs), defining them and calling for recognition of a focused and connected response to end the era of NTDs. As a family of illnesses, there are overarching commonalities and striking similarities involved in their control, and in localising their response to the most vulnerable populations. Chapter Three highlights such unique attributes before further narrowing down to focus on mycetoma itself, as one of the NTDs recently added to the comprehensive list of the World Health Organization (WHO). Throughout this section, the role of medical anthropology is underscored, acknowledging the bridging effect it may offer in understanding mycetoma and its complex – but selective – spread across Sudanese communities. I therefore explore the conditions that may act as *fertile grounds* for NTDs in general, with their relevance to the mycetoma response in Sudan. In order to localise and contextualise understanding around the disease, I further navigate the national environment of the disease in Chapter Five, elaborating on the national social, cultural, and policy environments in play. This links to Chapters Six and Seven, which highlight the communities and societies affected by the disease; in these chapters I elaborate on how such communities understand the illness, the stigma they convey, and the role of cultural and traditional leaders.

In the fourth chapter, using foundations and principles from medical anthropology as a guide, I illustrate the failure of a former health intervention for mycetoma prevention, recounting the implementation of the artificial animal enclosures. This case study illustrates the importance of understanding communities and their reactions to ‘taboo’ illnesses before planning interventions, policies, and services. Chapter Four details the intricacies of health interventions, comparing their intended use with their actual use in Wad Elnimear village and comparing this case with comparable failed health interventions in Sudan, Africa, and worldwide. In so doing, this chapter elaborates on how this case study speaks about power inequality, and how power dynamics played a vital role in the effectiveness of this intervention. The chapter further argues the finding in the artificial animal enclosure with James Scott’s (Scott, 1998) model of legalisation and power in health intervention, before concluding by emphasising the importance of understanding the cultural and social meanings attached to mycetoma, as these meanings can play a significant role in shaping health behaviours and health outcomes.

Building from the community level to the state level, the fifth chapter places mycetoma in relation to its broader policy context. First, I analyse relevant national policies, strategies, and guidelines related to mycetoma and its management in Sudan; in order to achieve this I use the Health Policy Triangle as a framework. Second, I explore existing approaches for treating and preventing mycetoma in Sudan and the current strategies undertaken to fulfil and implement these policies. I then describe the role of the Mycetoma Research Center (MRC), the leading player and the most dominant and powerful institute in the arena of mycetoma in Sudan. I explain the historical background of the centre, with a focus on how the power of the centre (shaped through its connections to various international bodies) also played a role in reducing the engagement of other key mycetoma management players such as the Federal Ministry of Health.

In Chapter Six, I elaborate on the concept of medical pluralism, with a focus on mycetoma. I show how the biomedical approach used by the MRC neglects other coexistent health systems of care, highlighting how traditional healers are visualised by the people working in the MRC as a source of delay in the management of mycetoma patients. I also emphasise the role of traditional healers as key healthcare providers and as first contact for most of the individuals affected by mycetoma, and explore the health-seeking pathways and the importance of social support for individuals affected by the disease. In so doing I question the attitude of biomedical providers towards traditional healers.

The seventh chapter illustrates the lived experiences of individuals affected by mycetoma and the complex relationship between their illness, livelihoods, and social integration – it illustrates their day-to-day lives. I argue that the lives of people with mycetoma are shaped by power exerted on them from varying levels and different directions. In this chapter I explore the different types of stigma encountered by people with mycetoma in the study site; the findings indicate various stigma themes such as individual, social, structural, and institutionalised stigma, and recovery challenges.

The final chapter – Chapter Eight – discusses the research results and findings and relates them to each other across all levels of health system literature before weaving these together to build recommendations and suggestions for developing evidence-based preventive strategies that are both culturally and socially sensitive.

Chapter Two

Research Method in Context

Chapter Two: Research Method in Context

Mohamed Elsheikh in a nutshell: where worlds meet

I grew up in a family of physicians and biomedical researchers, and have lived most of my life in Khartoum, the central city of Sudan, graduating from the top-ranked and the most prestigious university in Sudan, the Faculty of Medicine (University of Khartoum). Immediately after graduation, I became part of the teaching staff in the department of community medicine, and I practised medicine for two years. This PhD represents a transition from my previous position as a physician to my new position as a medical anthropologist and physician; from a physician who unconditionally accepted the insights of the biomedical sciences to one who acknowledges the importance of the social sciences, and from a quantitative researcher to a qualitative researcher; from an urban health research centre setting to a rural location. This transition was never going to be an easy one. I began my anthropological training by adopting a different mindset and different ontological perspectives, moving beyond the apprehension of one single truth as a physician to accepting and working with the notion of multiple truths. I moved from being the recipient of a guided reading to critically appreciating the contributions of various authors.

One of the main differences between social science and the biomedical sciences is the choice of which scientific approach to take when studying a phenomenon. While biomedical research often adopts a realism approach, most of my anthropological work is conducted through the lens of relativism. In the early days of my anthropology training, I was overwhelmed with these approaches, the choice of the best theory for my work to adopt, how research should be conducted, what assumptions anthropologists can make, and which approach is the best way to gain knowledge about the world. So, is realism better, or relativism? Should I go to the field with a white, blank mind, or should I go with preformed theory?

Realists believe that knowledge about the world can be acquired through organised and systematic experimentation. Fletcher (1996) states that realism is focused mainly on behaviour and that empirical research is the ‘cornerstone’ of the scientific method (Fletcher, 1996). This approach is widely used in psychology to study behaviour and gain ‘facts’ about the world, which can then be used to build psychological theories (Cacioppo et al., 2004). Relativism, on the other hand, offers an alternative approach to realism. Relativists argue that the human mind creates the world, and that the realism approach is no more rational or trustworthy than ordinary thinking (Cacioppo et al., 2004; Fletcher, 1996) suggested that the relativist approach argues that theoreticians should recognise that all forms of theories are worthwhile, and the key is to evaluate the relative informativeness of each theory. This indicates that all theories are valid, but they are based upon the relative ideas and assumptions of the theoretician who put them forward. The theoretician’s relative ideas and beliefs are based on societal contexts that “are part of the defining statement” (Kagan, 1964), meaning that what is stated is relative to the state of the individual and the context in which it is said. But which approach should I take, and what does this mean for anthropology?

Qualitative methods supplement and complement the understandings revealed by quantitative methods and are also a fertile source of hypotheses for future inquiries of both types. Despite the distinctions between the two methodological approaches, both possess structures and means of evaluating results which, when applied correctly, are rigorous. In recent years, the discipline of clinical epidemiology has established the decisive importance of analysing and evaluating clinical practice, and the appropriate inclusion of qualitative modes of enquiry will greatly enhance the process. True understanding in medicine cannot be achieved without incorporating qualitative methods into the research arsenal; such inclusion reiterates a canon of sound investigation, that is, that the methods employed should befit the question asked and not vice versa (Lakshman et al., 2000).

Sennar State: the unfamiliar land in my own home

At the beginning of 2018, as the research progressed, I relocated to Sennar, in the south-east of Sudan, to investigate the experience of individuals affected by mycetoma. I started by focusing on my first rapid ethnographic assessment of the artificial animal enclosure (see Chapter Five). As a Sudanese individual, on Sudanese land, working with Sudanese study participants, there was a noisy unfamiliarity. Sudan is home to over 500 tribes, with many preserving their unique traits against the test of time. With my two feet, I was walking into a history, a cultural cohesion, and a ceremony that I was not privy to. The community had ‘been there’ before me, and would continue to ‘be there’ long after I was gone. I was a mere visitor, a stranger who happened to live within the same borders once imagined by a British man. Living in Khartoum, my microcosm was limited; in the next section I detail the differences and similarities between myself as a wealthy Sudanese citizen from the capital, and the impoverished community of individuals living in rural Sennar.

Where does my knowledge end, and theirs begin?

We have a country that binds us, a culture, and values – but not enough in common. Intellectualism is isolating, it projects a hierarchy in itself. I first needed to break the social scales that 'visitors' before me had commonly painted. I put on my traditional hat and Sudanese *jalabiya* (traditional white robes) and wanted to simply have some conversations with the people of Sennar.

Coming in as an affiliate of the Mycetoma Research Center (MRC), I could sense some lingering tensions: "Why are you here?" "What do you want from us?" "Is this for our good or for yours?" Trust would be harder to earn if the community sensed an alternative agenda, if I was seen as an "extractor who doesn't know". I soon found out that engaging with the community during my PhD was about *them first, and about the research second*. Being a Sudanese doctor, speaking the same language, and being of the same religion greatly facilitated the recruiting of participants and gathering of experiences that are usually bypassed. In a time of political instability, this was not their only option – strangers were often seen as 'spies' and 'operatives' – and I had to proactively deconstruct these doubts in order to establish my presence as a different sort of visitor, one seeking to learn from them.

After weeks of relationship building, I established that the community's knowledge was an undiscovered source of intellect. It became clear to me that they really wanted to speak out about their experiences with the illness, but had never been asked before. Even despite the existing gender norms, women reached out to share their experiences with me. Several Sennar residents expressed confidence in me as an insider in terms of nationality and language; better than would have a non-Sudanese researcher, I was able to understand and more clearly represent the residents' experiences and struggles, as well as their desire to express their hidden reality to an outsider in the hope that this would help to represent them to the wider community. My being an insider in these respects also increased the residents' comfort level and assisted in developing a rapport – the moment they heard my accent, one could hear the sigh of relief and feel the atmosphere relax.

Studying the unfamiliar offers several advantages. First, because the researcher is 'ignorant' and the respondent is in the expert position, it is an empowering experience (Berger &

Malkinson, 2000). However, studying areas where the researcher lacks immediate points of identification or direct experience can also present challenges (Fawcett & Hearn, 2004). Some scholars (e.g., Fontes, 1998) have argued that a researcher cannot fully comprehend what it is like to be in certain situations they have not personally experienced. I have learned to embrace the familiarity, but even more so our differences – to acknowledge what I do not know, and to learn from the communal and tribal wisdom that I have access to in my own home.

Research setting, approach, and context

This thesis is based on ethnographic fieldwork conducted between 2018 and 2021. Ethnography is one of the most intensive and in-depth observational qualitative approaches (Candea, 2010). Ethnographies help us to develop a detailed description of how different peoples experience, interpret, and structure their lives; they describe people in terms of their 'natural living'. Indeed, ethnography is a form of interpretative understanding whereby the ethnographer is the research instrument (Fetterman, 1989).

I gathered the data from participant observations, and through involvement in participants' daily lives and activities. I used a range of data collection tools, starting with systematic observation and the keeping of daily field notes, in which the significant events of each day were recorded, along with the informants' interpretations. The initial observations focused on general, open-ended data collection, derived from individuals affected with mycetoma. In-depth interviews (both formal and informal), focus group discussions, participatory observations, and analyses of key documents were conducted. I also implemented a snowball-like investigation, further exploring and questioning relevant findings, and interrogating the different perspectives around mycetoma.

A total of 82 interviews were conducted: eight decision makers were affiliated to the Federal Ministry of Health (FMOH), some of whom were from the Department of Communicable and Non-Communicable Disease Control, which is responsible for neglected tropical diseases (NTDs) in Sudan, while four government officials were affiliated to the Sennar State Ministry of Health, all of whom were related to the mycetoma programme in the state ministry. Additionally, a total of six interviews were conducted with staff members, physicians, and researchers from the MRC.

To ensure a comprehensive understanding of the community's viewpoint, in-depth interviews were also conducted with a diverse range of individuals in Wad Elnimear village. Thirty interviews were held with members of the Wad Elnimear community, enabling an exploration of their knowledge, experiences, and perceptions regarding mycetoma. In addition to community members, interviews were conducted with community leaders who were closely associated with the area. Twenty interviews were conducted with patients who had first-hand experience of the disease, shedding light on their journey, challenges, and coping mechanisms. Furthermore, eight interviews were conducted with caregivers, who play a crucial role in supporting and caring for individuals affected by mycetoma. Lastly, insights from traditional healers were gathered through two interviews, recognising their traditional practices and potential influence on the management of mycetoma disease.

To document these findings, I transcribed discussions, denoted key observations, and captured photos and videos to support the emerging findings and conclusions. I started with a short visit that was conducted to investigate a project conducted in Wad Elnimear village, one of the highly endemic areas for mycetoma disease. The visit captured not only what I heard, but the environment and ethos of the study location too, including the climate, social behaviours, village events, and day-to-day routines that I observed.

The main emerging question, the one many qualitative researchers eventually have to face, was: whom do I talk to? For me, personally, I was eager for a variety of perspectives and insider views: those representing the different aspects of power, position, and patronage; those in the thick of it and those who were observing from afar; the young, the old, and the elders; those of the state as well as those who stood against it. I was keen on capturing their voices – all of their voices – especially those of the ones left behind. This research captures a variety of actors across Sudan, including the Sudanese public (from those invested in mycetoma, to those who have not heard of it), biomedical health professionals, traditional healers, academics, religious leaders, community heads, volunteers, and government officials across localities, at state-level, and nationally. Most importantly, the research captures the narratives of people infected and affected by mycetoma, including their families and caregivers.

Conducting research in Wad Elnimear village

Wad Elnimear refers to the (mostly Arabic-speaking) area of eastern Sennar State in the south-east of Sudan, which comprises a large group of houses built of materials ranging from mud and animal dung to tree branches and trunks. A notable number of houses had no surrounding walls, while only a few were built from bricks. A few kilometres from the Dinder River, the area is surrounded by dry sand that extends towards the nearby Wad Onsa village in the north.

There are distinct animal enclosures near to every house, with cows and goats contained within them. The village is dusty, and the region is known for hot and dry spells that last for days in April, and a very rainy season in July and August (see Figures 4, 5, and 6).

Figure 4: The northern part of Wad Elnimear village in the eastern part of Sennar State, Sudan.

Figure 5: A traditional animal enclosure site, in front of a house in Wad Elnimear village.

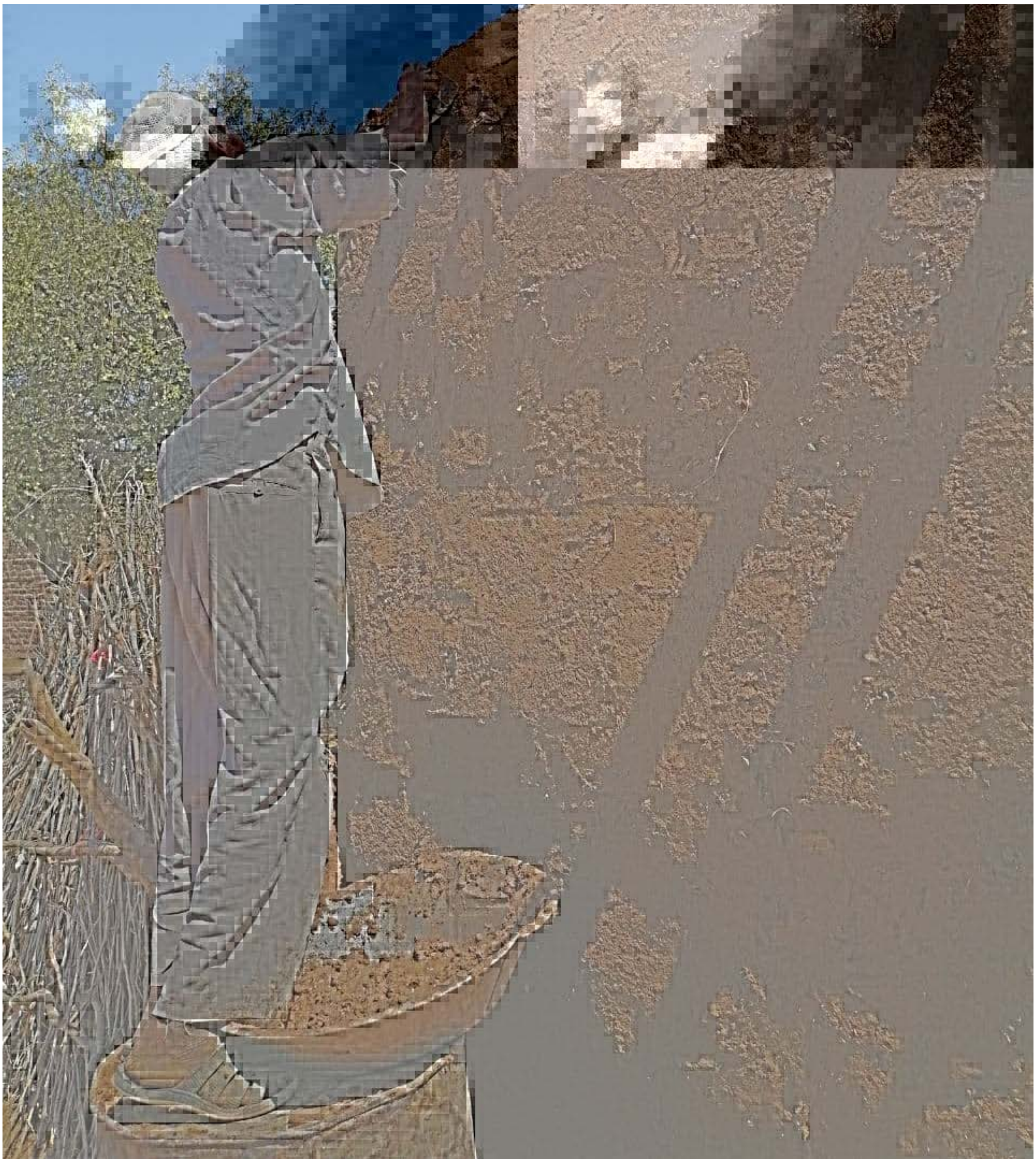

Figure 6: One of the Wad Elnimear villagers building a room of mud inside a house.

This study's fieldwork was built around local lifestyles of a semi-nomadic nature, and was grounded between Wad Elnimear and Wad Onsa villages. As indicated earlier, the choice of Wad Elnimear as location was due to the high endemicity of the disease there. I was also based in Wad Onsa village so as to have visibility of the nearby villages towards Wad Elnimear. I also explored more than ten additional nearby villages, so as to have a broader view of the areas of Eastern and Central Sennar.

My connection with the MRC played a crucial role in the first stages of data collection. Colleagues from the MRC provided me with a connection to one of the community leaders in Wad Onsa village, and informed his family that a doctor ‘from Khartoum’ (from ‘the outside’) was moving to the area. It is to be noted that my living with one of the community leaders in the region gave me additional power as an outsider, and may have influenced my positionality. However, having help from a community leader in such an unstable political setting was an important entry point. Later, I moved to a different family in order to reduce the influence of the high social power that I gained through this community leader and to explore the setting from a different (observational and relational) positioning. I was a family guest even before I set foot in Wad Onsa. Although the first few weeks of fieldwork were considered on behalf of the MRC, through snowballing fieldwork and data collection, further independent research developed from the initial introductions. Subsequently, my fieldwork evolved from my ‘only’ being a doctor, and representative of a Wad Onsa leader’s influence and power, although some of these persons remained a point of reference throughout my fieldwork.

Upon talking to the villagers on my very first day in Wad Onsa village, one reality became very clear to me – their lives were much bigger than just their medical wellbeing; their home, livelihoods, culture, and religion all had a weight I was not used to experiencing within the small confines of a clinic’s four walls. There was an entirely new world that a purely medical lens would not have been able to see. I could not access their realities unless I put mine as an urban medical professional aside; after all, the way in which people talk to a doctor is often worlds away from how they would talk to a friend.

It was necessary that my medical identity be put on hold to fully appreciate the wider complexities involved. As long as I was connected with the MRC, the accompanying assumptions and notions implied that I was exclusively ‘interventional’ – a ‘campaigner’ here to conduct another vertical surgical intervention. That needed to change. Not only did I not want the villagers to view me as a medical doctor, I certainly did not want the social power that came with being a physician – this would have significantly affected the results, and likely yielded less regarding the livelihoods of people living with mycetoma. As difficult as it would be to ‘do nothing’, the medical hat needed to come off. I pushed myself forward as “a simple visitor that is keen to learn”. Throughout the data-collection journey, as detailed across all the chapters in this study, I critically consider the influence my identity and career may have on my interpretations and continually question, “what if … I weren’t?”

My early weeks in the village were spent sharing daily routines with my multiple research informants, hosts, and companions, getting to know the host family’s neighbours and relatives, and visiting other mycetoma patients’ families, located in Wad Elnimear, Wad Onsa, and in the surrounding rural areas. The timelines and duration of my visits to the villages were hugely varied. These were principally determined by the circumstances that the villagers were experiencing and their schedules – my programme was based primarily on the invitations that I received. For example, I might spend weeks with some individuals, and with others just a few hours, depending on their invites. I might spend one complete day, or, alternatively, several days and weeks, and then sometimes just a few hours. I would be attending a family funeral in one of the villages when I would receive a call from another individual telling me about his son’s wedding, or I could just go along to the big Wad Onsa market every Saturday to socialise and to meet other people, either from, or living outside of, Onsa village.

My movements were not necessarily regulated by my own preferences and research plans – although I tried, and partially succeeded, in prioritising my research objectives – but were, most often, the result of a gentle balance between the hospitality offered by different people and households, and my own attempts to explore various aspects of the research. In Wad Onsa and Wad Elnimear, most people went to bed in the relatively early hours of the night, especially when the electricity was out. Hence, I spent the nights principally with my research assistant – whenever it was possible – transcribing and translating the interviews that we had received. Besides this, I would also write down and analyse the conversations, organise my field notes, and plan for the next interviews and the research gap(s) that I wanted to fill (see Figure 7).

Figure 7: Myself working at night with a mobile flashlight to document field observations.

In this chapter, I present the methodological approaches of my study, and describe the different methods that I used, along with their justifications. Broadly speaking, I took a qualitative methodological approach, with a primary focus on ethnographic observation so as to generate rich, detailed, and in-depth knowledge, all useful for exploring people's experiences and perceptions. The various types of research methods are not inherently better or worse than each other based on their intrinsic qualities, but have varying suitability for different purposes. Qualitative and quantitative research strategies each have different epistemological strengths and complement one another: quantitative methods examine the effects of specified circumstances (the independent variable) on an outcome of interest (the dependent variable), in ways that can be expressed numerically (Lakshman et al., 2000); qualitative methods then explain these effects by taking a holistic perspective, which preserves the complexities of the phenomena under study.

Following a series of initial pilot interviews, I widened the research inquiry towards understandings of the nature of the disease, and its subsequent management(s) across different contexts. Thus, I embarked with different frameworks and approaches for research, rather than following a rigid research design, which consequently helped me to become acquainted with a large topic area, without becoming fixed upon preconceived themes. I was inspired primarily by a grounded theory approach, in developing working hypotheses as the research progressed, and applying the theories of others; as Locke et al. have put it:

> grounded theory studies do not start with a theory – they end with one … Also, because theories pronounced tend to be very specific to the content studied, they often have strong implications for the design of effective practice. What they lack in terms of grand generalization they gain in terms of applicability. (Locke et al., 1998)

Why critical medical anthropology?

Anthropology’s being a branch of social science (Greenhalgh, 2018), its hallmark is the exploration of the complexity and nuances of human interactivity and cultures. As a research discipline, anthropology combines humanist and social science strategies (Hyman, 2013). This complexity becomes more prominent because of behavioural changes that are a continuous process, and that vary across different contexts.

Medical anthropology goes beyond the conception of human communities as just a collection of interacting individuals, acknowledging instead that humans live in multispecies communities *along with* disease vectors and zoonotic pathogens (Singer, 2015). Changes in interactions in any of them can lead directly to changes in individual health, and every human being is a moving community, full of interacting species. This analytic perspective also recognises how human activities and understandings, for example, cultural conceptions and/or stigmatisation, can contribute to the spread of certain diseases, and how these cultural conceptions of diseases change with time, and ultimately affect the social responses to these conditions (Singer, 2015).

Over the past two decades, anthropological approaches to health and illness have confirmed their value in facilitating more nuanced understandings and in responding to certain diseases, such as HIV, Ebola, SARS, malaria, influenza, kuru, tuberculosis, and other infectious diseases (Ramin, 2007). Medical anthropological research has achieved this primarily by identifying and assessing human behaviours linked to both prevention and treatment, as well as by analysing their role in the creation of lived experiences, and in forming the bindings between the framings of social groups, communities, and the ‘big picture’ of global processes, and the international social relationships with these microscopic entities (Zaman et al., 2020a); these connections create pathways that connect human bodies, cultural and social systems, and health. For example, one of the earliest efforts to directly confront and address these issues within so-called ‘peasant research’ was the book *The People of Puerto Rico* (Opler et al., 1957). Based on a series of local community studies carried out in different regions of the island by Julian Steward’s students, this book described and analysed each local community, to fit these communities together by examining the larger economic and historical processes that shaped their development, and, finally, to locate social developments in Puerto Rico (Singer, 1994). Medical anthropological work also contributed to the discovery of kuru disease in the late 1960s, located among the South Foré people of New Guinea, and identified by medical anthropologist Lindenbaum (Singer, 2015).

Within the field of NTDs, the ‘gap’ between knowledge and practice is frequently large (see, e.g., Candea, 2010; Willerslev, 2007). Where behavioural changes are necessary, it is, however, also important to acknowledge that such changes are affected not only by knowledge, but also by structural conditions (Prentice & Trueba, 2018; Trueba, 2014; Trueba et al., 2022). Most significantly of all, it is vital to acknowledge that context is not meaning and vice versa; structural conditionality is critical, but not absolute. The social sciences can provide theoretical insights and methodological approaches so as to analyse the framing of programmes and interventions, as well as to then make interventions contextually sensitive (Zaman et al., 2020a). Social science and anthropological perspectives are vital to unpacking the social and political determinants of any disease (Trueba 2022). This perspective is underutilised even further in the field of the NTDs (Zaman et al., 2020a). This is why the term “second translational gap” has been used to describe this disconnect between the development and the implementation of evidence into practice within public health in the Global North (Lau et al., 2014), but it is, however, also found worldwide (Ogilvie et al., 2009; Zaman et al., 2020).

Critical medical anthropology is a subfield of medical anthropology that emerged in the 1990s; it provides a critical perspective on medical anthropology, and examines the social, political, and economic forces that shape health and illness patterns across different cultures and societies (Singer et al., 1990). It examines how these factors interact to influence health outcomes and how they are shaped by cultural and historical contexts. Critical medical anthropology also emphasises the importance of understanding the lived experiences of individuals and communities and the need to challenge power structures that perpetuate health inequities and social injustices (Baer et al., 1986b).

The origins of critical medical anthropology can be traced back to the political and social changes of the 1960s and 1970s. During this time, there was an increasing focus on social justice and human rights, which led to a growing interest in the social determinants of health. Key authors in this field include Nancy Scheper-Hughes, Merrill Singer, and Paul Farmer, among others (Baer et al., 1986a; Farmer, 2004). In 1983, a series of sessions entitled 'Beyond Medical Anthropology: A Political Economy Critique of Health', and 'Toward Critical Medical Anthropology', held at the annual meeting of the American Anthropological Association, ignited the idea of conducting a critical analysis of health and illness from the perspective of social and cultural contexts 1986b). The latter session was organised by John Johnsen and Hans Baer, and was designated an Invited Session of the Society for Medical Anthropology, and a large measure of the Special Issue of Social Science & Medicine grew out of the proceedings at these two sessions. Later, Baer and his colleagues helped in the development of the medium of critical medical anthropology. They were concerned with the ways in which power differences shape social processes, and they argued that: "the dominant ideological and social patterns in medical care are intimately related to hegemonic ideologies and patterns outside of medicine" (Baer et al., 1986b). They started from an initial perspective of capitalism.

A critical medical anthropology tries to achieve deeper insights into health and illness than are presently provided by middle-range theories and interactional research, principally by addressing the questions of who has primary control of key biomedical institutions, and what are the implications of such control. Critical medical anthropology views the individual as a political, social, and cultural being inside of the society. This is a complex acknowledgment of a political–sociocultural individual, who acts as part of the larger community, affecting this community and, equally, being affected by it, which, in turn, then also affects, and is affected by, a larger macro-influence in term of policies, strategies, and guidelines. When this individual then becomes ill, they still play the role of the political, social, and cultural individual who is affected by all of these powers. We cannot simply blame these individuals for choosing a traditional healer over biomedical westernised medicine, or for having and living with stigma, without also considering other forces at the meso and macro levels.

One of the main contributions of critical medical anthropology is its emphasis on the importance of understanding the lived experiences of individuals and communities. Critical medical anthropology delves into the intricate relationship between health, illness, and society. It recognises that health is not solely determined by biological factors but is profoundly influenced by cultural, political, economic, and historical contexts, and that health outcomes are not solely determined by individual behaviours or genetics but are deeply rooted in social structures, such as poverty, discrimination, and unequal distribution of resources. By adopting a critical lens, critical medical anthropology sheds light on the power differentials, inequalities, and injustices that exist within healthcare systems and the broader social fabric (Farmer et al., 2006). It explores how power is exercised by various actors, including healthcare providers, institutions, governments, and pharmaceutical companies. By examining these power dynamics, critical medical anthropology reveals how certain groups, often marginalised or disadvantaged, face unequal access to healthcare resources, services, and decision-making processes (Lupton, 2020). Critical medical anthropology aims to uncover the social inequalities that contribute to health disparities and highlights the importance of addressing social determinants of health and advocating for policies that promote equity and social justice (Baer et al., 2020).

Another crucial aspect of critical medical anthropology is its critique of the dominant biomedical model of healthcare. It questions the reductionist and individualistic approach of biomedicine, emphasising the need for a more holistic and culturally sensitive understanding of health and illness. Critical medical anthropology encourages the incorporation of diverse healing traditions, indigenous knowledge, and alternative healthcare practices into mainstream healthcare systems (Lock & Nguyen, 2023). While critical medical anthropology (CMA) provides valuable insights and critiques, it is also necessary to understand its limitations and potential biases. A key point of critique is not the dismissal of the potential of biomedicine to save lives. Rather, practitioners like Merrill Singer and Paul Farmer focus on critiquing the actual implementation and distribution of biomedicine. They emphasise the disparities and barriers in accessing biomedical resources and healthcare services. This perspective is crucial as it recognizes the significant contributions of biomedicine to medical knowledge and technological advancements, while also highlighting the need for a more equitable distribution and accessibility of these life-saving interventions in various societal contexts

In recent years, there has been a growing interest in critical medical anthropology among scholars and practitioners. This is reflected in the increasing number of conferences, journals, and publications that focus on this subfield. As the world continues to face complex health challenges, such as the Covid-19 pandemic, the insights and perspectives provided by critical medical anthropology will only become more important in shaping our understanding of health and illness.

Why ethnography?

Aiming at obtaining a detailed understanding of human behaviours, attitudes, and experiences (Mohajan, 2018; Tong et al., 2012), I employed a qualitative approach because I believe that this method of research can pull together data across different contexts in ways that primarily biomedical research cannot. It can lead to the generation of new theoretical or conceptual models, identify research gaps, inform the development of primary studies, and provide evidence for developing, implementing, and evaluating health interventions (Tong et al., 2012).

The method that sets anthropology apart from other disciplines is ethnography, the continuous process of exploring in depth the ‘whys?’ and the ‘hows?’ of human cultures, behaviours, and expressions. Using this ethnographic method, anthropologists can uncover unexpected insights that are best gained by studying a topic in person, in situ, over time, and from diverse perspectives in their unique context (Hyman, 2013). Ethnography is concerned with the collection of data from the everyday encounters that shape human life. Perhaps, because so much cultural behaviour is perceived as either ‘normal’ or ‘natural’, ethnography emerged from a fascination with the apparently ‘foreign’ and ‘strange’ civilisations that evolved in the modern period, often as a result of colonisation, missionary activity, and international trade (e.g., Geertz, 1973, 1988; Humphrey, 2008; Hylland Eriksen, 1995; Ingold, 1994).

The primary job of anthropology is to contextualise sociocultural circumstances, so as to investigate human behaviours, languages, familial patterns, rituals and beliefs, economic and political systems, child rearing practices, life phases, arts, crafts, and technology, in order to further the research of such cultures. Anthropologists also often conduct research in the original languages of their subjects in order to gain insights into these topics. This is not always easy, or possible, and they often need the help of interpreters and hired informants (Abraham, 2003)**.**

Harry Wolcott defines ethnography as: “the business of inquiring into other people’s business”, and van Maanen adds that it is: “a wonderful excuse for having an adventurous good time while operating under the pretext of doing serious intellectual work” (Hammersley, 2018). None of these definitions enhance the public image of ethnography. Other scientists elaborate further on the definitions of ethnography; for example, Erickson describes ethnography as a description of people and their actions or behaviour: it describes the everyday routine of culture. Ethnography belongs within the field of qualitative research, which, as Jerome Kirk and Marc. L. Miller write:

> is a particular tradition in social science that fundamentally depends on watching people in their own territory and interacting with them in their own language, on their own terms. As identified with sociology, cultural anthropology and political science among other disciplines, qualitative research has been seen to be ‘naturalistic’, ‘ethnographic’ and ‘participatory’. (Kirk, 1986)

Ethnography involves participation with, and the observation of, the ‘other’. Ethnographers draw their data from their fieldwork by observation. Ethnography is a holistic approach that provides a thick description of interactive processes, and involves the discovery of important recurring variables in a society as they relate to one another, both under specified conditions and as they affect or produce certain results and outcomes in a society. It is not a case study, which, in contrast, narrowly focuses on a single issue, or a field survey seeking previously specified data, nor a brief encounter (Hammersley, 2018).

The ethnographic method uses multiple data collection techniques, including: participant observation, interviews, focus groups, and document analyses. This is done in order to construct holistic and contextualised views of the phenomena under study. During their research, anthropologists make observations and pursue these perspectives from diverse angles and in various ways. They observe and talk with people from different social categories, who have varying relationships to the phenomena under study, and who conceptualise and respond to those phenomena in their own unique ways; thus, in my research I bring in different points of view from different categories: people affected by mycetoma – such as patients, caregivers, and family members, – policymakers, researchers, and community leaders as well as traditional healers and community members from different areas. Anthropological inquiry combines information about people’s thoughts gathered through interviews with information collected by observing their behaviour and social interactions. In the context of mycetoma, this included interviewing and observing doctors, office managers, policymakers, caregivers, and patients. This was done so as to explore the multiple and distinct ways in which various individuals experience the disease and/or conceptualise it (Hyman, 2013).

In the ethnographic process, the anthropologists themselves often become key research instruments (Fetterman, 1989; Zaman, 2013). They immerse themselves in the rich, largely qualitative data sets that result from their research, and conduct iterative analyses to identify emerging themes and gain insights about the meaning of the data. The goal of an anthropological approach is a critical interpretation of the data that is well described, and that provides valuable insights. In this sense, medical anthropology has much to contribute to the field of mycetoma management, in which researchers aim to not only evaluate health implementations, but also to uncover contextual meanings and reasons behind those descriptions within a rapidly evolving healthcare system, and hence can help in, for example, developing more culturally sensitive health interventions. An anthropological approach can assist in the co-designing of a community health prevention plan that involves all mycetoma stakeholders: from the patients and their community, to healthcare providers and decision makers at the national and international levels, and including academics in universities and research institutes, as well as both governmental and non-governmental organisations (NGOs).

This anthropological approach necessitates the investigation of issues from multiple perspectives and by multiple means; this includes the collecting of data as expressed by clinicians, other staff members, and their patients. Anthropological evaluations are designed to identify the shared cultural meanings between and among different groups of what can be referred to as ‘stakeholders’ (such as providers, staff, and patients), and to determine how culture is constructed through the practice. A longitudinal evaluation from an anthropological perspective involves documentation of the dynamic changes in practice cultures, and patients’ interactions with this transformation (Hyman, 2013).

Participant observation is an in-depth, qualitative, study approach and design that uses a logical process of inquiry that is open-ended, flexible, opportunistic, and requires constant redefinition of what is deemed to be problematic, based on facts gathered in concrete settings of human existence. Participant observation places a special interest on human meaning and interaction as viewed from the perspective of people who are insiders or members of particular situations and settings; it involves the performance of a participant role or roles and establishing and maintaining relationships with natives in the field; the researcher uses direct observation along with other methods of gathering information. Ultimately, the methodology of participant observation aims to generate practical and theoretical truths about human life grounded in the realities of daily existence (Jorgensen, 2011).

Participant observation is especially appropriate for the research problem when little is known about the phenomenon under investigation, where there are important differences between insiders and outsiders, and when the phenomenon of investigation is observable within an everyday life situation or setting; it also very helpful in challenging assumptions (Jorgensen, 2011). As a disease formally labelled as ‘neglected’, mycetoma in Sudan captures all three deficits. Hence, participant observation is especially appropriate for exploratory studies, descriptive studies, and studies aimed at generating theoretical interpretations and effective intervention strategies. Though less useful for testing theories, the findings of participant observational research are certainly appropriate for critically examining theories and other claims to knowledge. Observation and attentiveness to detail were thus critical in assessing mycetoma in Sudan, and indeed the most suitable methodology in answering our principal research questions.

In the next section, I detail the frameworks that guided my data collection, and also elaborate on the research tools that I used.

Data analysis frameworks

This section details some of the key data analysis approaches and frameworks that guided my data collection strategy. A framework method for the management and analysis of qualitative data has been in use – in various forms – since the 1980s (Lewis et al., 2014). This research method originated in large-scale social policy research, but is becoming increasingly popular within medical and health research (Bauer, 2013). The use of logical frameworks helps in the identification of commonalities and differences within and across qualitative data, before then focusing on the relationships between different parts of the data, and thereby seeking to draw descriptive and/or explanatory conclusions clustered around themes. The original framework method, which I have adapted according to the demands of my specific research project, was developed during the late 1980s by Jane Ritchie and Liz Spencer, from the Qualitative Research Unit at the National Centre for Social Research in the United Kingdom, for use in large-scale policy research (Lewis et al., 2014). It is now widely used in other areas, including health research. It provides clear steps to follow, and produces highly structured outputs of summarised data. However, caution is recommended before selecting the method, as it is not a suitable tool for analysing all types of qualitative data, or for answering all qualitative research questions, nor is it an ‘easy’ version of qualitative research for quantitative researchers.

The framework method has most commonly been used for the thematic analysis of semi-structured interview transcripts, although it could also, in principle, be adapted for other types of textual data, including documents (Harding et al., 2017). The nature of the framework method is deductive, because its methodical processes and ‘spreadsheet’ approach seem more closely aligned to the quantitative paradigm (Pope & Mays, 2009). I found this useful, as it allowed me to use one analytical framework that enabled simultaneous quantitative–qualitative appreciation of field-based research, thereby supporting a more nuanced format for advanced data analyses.

For my research, I used the multi-level framework developed by Goffman (Pescosolido et al., 2008). The use of this framework, as is illustrated below, allowed me to understand the multiple factors that influence an individual’s relationship with the social world. Since my research also aimed at understanding the policy situation of mycetoma management in Sudan, I combined this multi-level framework with Walt and Gilson’s (1994) policy analysis framework. This combination was necessary to fully explore an individual’s relationship with the social world, which requires the use of a research approach that acknowledges these multiple levels of analysis; both frameworks guided my data collection and analysis.

Framework integrating normative influences on stigma (FINIS)

FINIS focuses on the central hypothesis that several different levels of social life set the normative expectations that then play out in the process of stigmatisation (Pescosolido et al., 2008). These levels are: the micro, or psychological and sociocultural level, often referenced as individual factors; the meso, or social network, otherwise known as organisational level factors; and the macro, or societal-wide factors. The second framework used is the health policy triangle framework, developed by Walt and Gilson (1994), which analyses part of our data at the macro level. The four categories of ‘content’, ‘context’, ‘process’, and ‘actor’ also correspond broadly to the ‘what’, ‘why’, ‘how’, and ‘who’, within health policy analysis. This also connects both structurally and analytically with the appreciation of both qualitative and quantitative methodologies that I have made it a priority to emphasise within this section.

The three levels in this framework relate not only to stigma – as the FINIS framework was the main focus for this – but were rather more holistic, as follows:

The micro level

The micro level refers to the construction of the disease at the experiential level, and the subsequent attribution of the disease’s value/lack of value at an individual level. It then links these constructs to often-broader stereotyped beliefs, to then form the interpersonal evaluations of the afflicted person’s behaviour. Mental illnesses, in particular, can be easily identified, because of their overlapping impacts on both physical and purely experiential characteristics. If a person holds a devalued status, observers will ‘mark’ the problem as severe, hence the further endorsing of stigma. The social differences include race and age, and the more significant social differentiations between the targets (Zaman et al., 2020a).

The meso level

At the meso level, the framework focuses on the community members and how they conceptualise the disease, the cultural construction of the disease, whether there is any stigmatisation, and, if so, what the nature of the stigma is. It also focuses on the treatment system, treatment pathways, and the role of organisations designed to deal with societal problems. These issues represent a focus of the research, and while this presents a challenge to identifying the forces at work, they cannot be ignored. More generally, society’s social organisation reveals who can obtain power, and shapes how citizens view themselves and others within society (Zaman et al., 2020a).

The climates and cultures of treatment settings also, sometimes, have unintended, stigmatised influences, including the absence of hopeful messages from providers, which suggests that the very assignment of diagnosis itself may have the unintentional consequence of triggering stereotypes. For example, Pescosolido et al. (2008) mention that the stigma of psychiatric illness starts at the time of diagnosis, due to the belief that psychiatric patients do not recover.

The macro level

The macro level aims to contextualise the state of the national-level actor’s context through exploration of the existing health policies, guidelines, and strategies, as well as the decision makers and their standing points towards the disease. It provides an overarching ideology by categorising stigmatised groups, and providing clues to appropriate responses. The broader context embeds normative expectations in and through economic development, social organisation, and cultural systems, because each reflects access to social power (Pescosolido et al., 2008).

Walt and Gilson’s policy analysis triangle

Policy analysis is an established research area, method, and academic discipline in the industrialised world. Yet, its application to low- and middle-income countries has been limited, and the health sector, in particular, appears to have been neglected (Walt & Gilson, 1994). The macro-level impacts of mycetoma are explored here through a policy analysis of the National Health Guidelines, using the health policy triangle as an analytical instrument (Walt & Gilson, 1994).

The health policy triangle is grounded in a political economy perspective. It can help with monitoring, understanding, and planning a health policy. The framework has influenced health policy research in a diverse array of countries, and it has been used to analyse a large number of health issues, including: mental health, health sector reform, tuberculosis, reproductive health, and antenatal syphilis control (Walt et al., 2008). For example, in the 1990s, McKee et al. (1996) underlined that most cases of sudden infant death were preventable, while statistically supporting their argument with empirical evidence. However, this argument seemed to have little to no influence on governmental guidelines – the rise in sudden infant deaths did not concern those actors at the time. Kilic et al. (2014) have qualitatively evaluated the existing policies of the Turkish health system, so as to evaluate and develop appropriate policies for cardiovascular diseases, diabetes mellitus, and related risk factors.

The health policy triangle is a demonstration of four interacting, inter-relational, and non-separate factors – content, context, process, and actors – and, subsequently, it is a tool that is useful for the exploration of ignored political areas within health policy, and that can be applied to all levels of the economy (Buse et al., 2016a).

Actors in health policy comprise individuals, groups, organisations, and governments, serving as the focal points of the policy framework. Their influence on policy development is shaped by various aspects, including their history, culture, political agendas, and policymaking experiences, which in turn affect the contexts in which they operate and that develop their values and expectations. Actors, such as advocacy groups, play a critical role in influencing policy without seeking official political authority, instead expressing their concerns and sentiments about political issues. They can exert their power at different levels – locally, nationally, regionally, or internationally – often building networks with other stakeholders throughout the policymaking process.

Understanding the content of national policies, particularly disease management guidelines, is essential for policymakers. Analysing how a specific disease is mentioned in relation to others within policy documents offers insights into its conceptualisation and prioritisation at the policy level. The policy process involves understanding how power dynamics and systemic factors interact, shaping decision-making procedures. Contextual factors, categorised as situational, structural, and cultural, play significant roles in influencing health policy (Woldehanna & Volmink, 2004). Situational factors encompass temporary and unconventional events that impact policies, as exemplified by the HIV epidemic, which changed the focus of tuberculosis control policies due to increased susceptibility in HIV-positive individuals. Structural factors, such as a nation's basic features and civil society participation, also influence policymaking, as evidenced by the global increase in caesarean sections due to technological advances and economic development (Betrán et al., 2016). Cultural factors, including societal hierarchies and the treatment of ethnic minorities and linguistic differences, can lead to disparities in rights awareness and access to services. Understanding and considering these interrelated contextual factors are crucial in developing effective and inclusive health policies (Buse et al., 2016).

Document analysis

Policy documents have been an essential source for observing evolving policy understandings. Equally, documentary analysis also has evident limitations, in that dialogues, points of view, and other mediums and/or forms of information are not incorporated in a formal and official text. Shaw noted a number of practical advantages for employing documentary analysis, such as a lack of other sources at an early stage of policy innovation, but sees drawbacks in bias, superficiality, and being aspirational (Rachel et al., 2004).

In using policy documents as sources, I followed this by identifying aims and intended strategies, as well as their explanations. I was wary of taking textual interpretations at face value, and approached them with scepticism, seeking for alternate explanations and meanings based on underlying assumptions and ideologies. Because policy texts have limitations, I undertook qualitative interviews in order to obtain knowledge of policy that went beyond the official boundaries.

Specific, relevant key words were used to search various databases for documents relevant to the prevention and control of mycetoma in Sudan. The database of the Federal Ministry of Health (FMOH) was searched to find all documents concerning health policies, strategy, and guidelines (a total of 192). Internal websites, such as those of the FMOH and the MRC, were searched so as to find internal and unpublished documents in *addition* to documents taken from the Strategic Planning Department in the FMOH (a total of 28). Duplicate documents were then excluded. The content of the included documents was then searched using the term 'mycetoma', so as to extract mycetoma-related content. A full-text assessment was done on three documents; content analysis was carried out on the following three documents:

1- ‘Mycetoma Polices and Management Guidelines for Service Provision and Essential Good Clinical Practice 2017’, by the MRC – University of Khartoum, 2018.

These guidelines were developed by the mycetoma working group, located at the MRC (the WHO collaborating centre on mycetoma, Sudan), and were based on the MRC’s 25 years of experience in the management of more than 8,200 mycetoma patients. The policy set three main strategic objectives for compacting mycetoma: bridging the knowledge gap; improving access to treatment; and ensuring high service quality.

2- ‘Strengthening Primary Health Care in Sudan Through Family Health Approach Policy Options’. Public Health Institute, FMOH, 2016.

This policy mission is focused towards the availability of efficient, people-centred, high-quality, integrated care, which is also accessible to all members of the population throughout their life course, equitably across the regional, racial, ethnic, and socio-economic groups, and without financial hardship. This policy is intended to strengthen the primary healthcare (PHC) service delivery system and to enable efficient and equitable quality health services. This policy will, also, work to enhance the attraction, recruitment, and retention of family physicians, and to ensure the production of adequate and competent family physicians and allied health workers, so as to provide integrated people-centred health services at PHC level.

In this policy, mycetoma is considered as one of the 17 globally listed NTDs, nine of which are a recognised public health problem within Sudan under the communicable diseases section.

3- ‘Sudan’s Global Health Strategy 2015–2019’, by the Public Health Institute, FMOH, 2016.

This strategy aims at creating an integrated and coherent position on global health, and a consistent and cohesive approach-strategy towards global health, both internally and externally. It is also aimed at contributing to better health and wellbeing for the entire population in Sudan, through the increasing of competency, knowledge, and skills in global health. Outlining the interconnectedness of the priority areas within this strategy will help both to create and to raise further awareness on global health. The strategy will, therefore, provide a basis from which to foster capacity-building measures in the different sectors and across different educational institutes, in both the health and the diplomatic fields. Figure 8 shows the process of document analysis.

In addition, I also collected data through interviews with key informants, here defined as: those with significant responsibilities for the health system, for NTDs, and for mycetoma at national and district levels; this included respondents who are high-level officials from government and private organisations involved in dealing with mycetoma. A total of eight key informant interviews were conducted face to face, using a tape recorder, after taking informed consent, with no names or any other potentially identifying information included in the final report or publications.

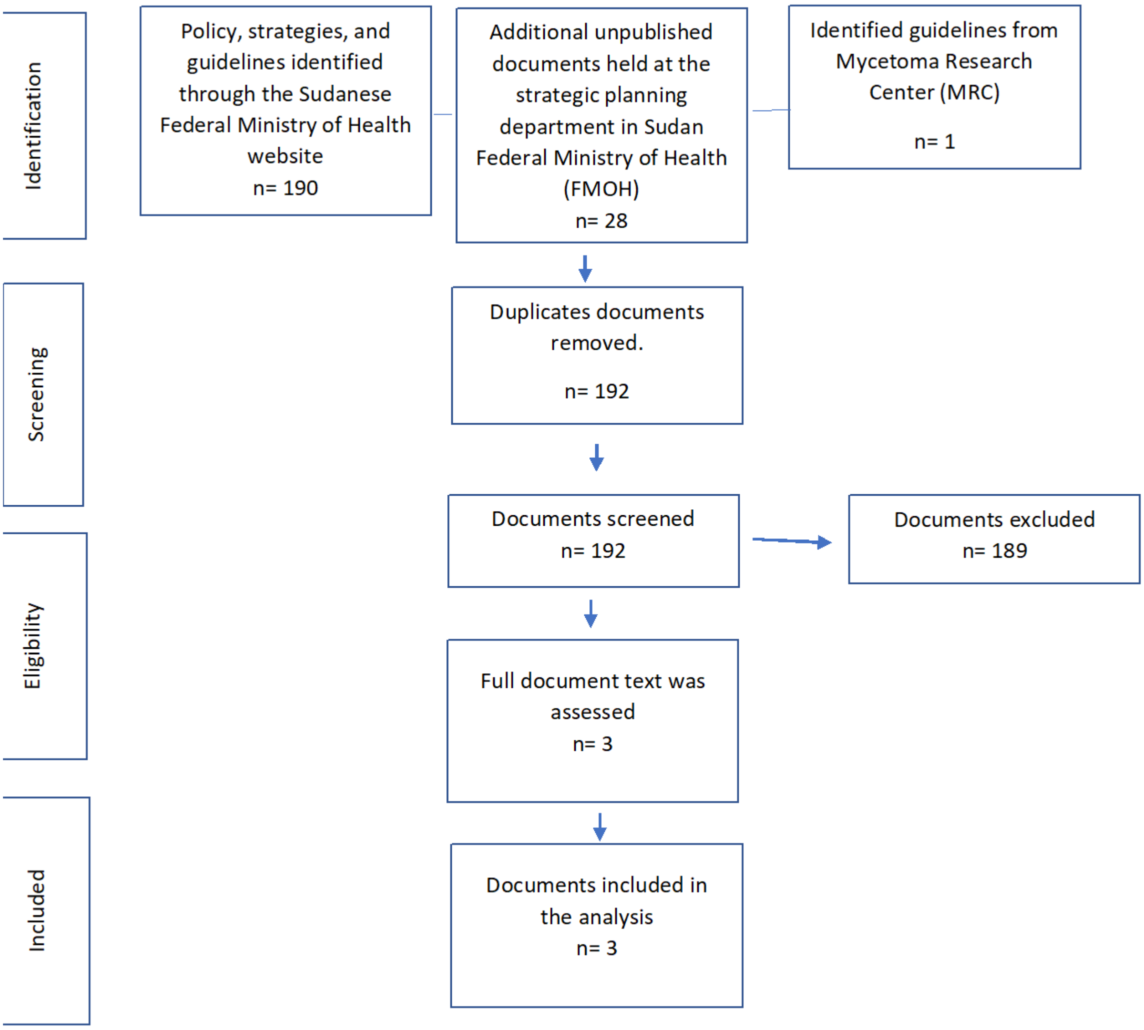

Figure 8: Flow-diagram showing the process of document analysis.

Ethical considerations

Ethical approval was granted by the Soba Teaching Hospital, University of Khartoum, IRB No. 27122018 (Appendix 1; see 221), and by the Research Governance and Ethics Committee at Brighton and Sussex Medical School, reference no. ER/BSMS9DHJ/9 (Appendix 2; see 223). All local and cultural ethical protocols were observed, and participants gave their voluntary consent for participation (Appendix 3; see 233). Consent was taken after conveying to the potential participants the necessary understanding of the motivation and procedures of the study, and the sources of information using the Participant Information Sheet (Appendix 4; see 234). Participants' identifying information was removed from the text.

All discussions/interviews were audio-recorded and accompanied by my field notes. Recordings were transcribed verbatim and translated from the national language (with account taken for regional dialect). Field notes were also taken during participant observation. During analysis I also used the NVivo version 12 program form for arranging the codes according to themes, using framework analysis (Gale et al., 2013).

This was after the Covid-19 pandemic risk assessment no. 4674RA (Appendix 5; see 236) was taken and approved in November 2020, so as to assess the risk of my encountering or transmitting Covid-19 during my fieldwork. As my study was ethnographic, face-to-face interaction and observation were crucial. Moreover, alternative methods, such as using a mobile phone or other virtual methods, were not feasible, because there was neither electricity nor mobile phone network; the Letter of Ethical Approval from the Soba Center for Research and Audit (SCAR) Committee to continue the fieldwork in Sudan is included (Appendix 6; see p.238).

I was granted ethical clearance to commence my fieldwork from the Brighton and Sussex Medical School (BSMS) Research Governance and Ethics Committee (RGEC) on 24 November 2020, reference no. (ERA/BSMS9DHJ/9/1) (Appendix 7; see 239).

All photos from the fieldwork were taken by me unless stated otherwise. All the participants consented to the images, agreed to have the pictures taken, and were informed of their intended use in the thesis.

More reflections throughout my journey

The main purpose of this section is to present a reflective account of my PhD journey and the challenges and difficulties that I encountered during my journey. Qualitative research is affected by whether the researcher is a part of the research and shares the participants' experiences. Therefore, reflexivity has been increasingly recognised as a crucial strategy in generating knowledge through qualitative research (Ahmed et al., 2011).

Reflexivity is a process of looking both inward and outward with regard to the positionality of the research and the research process (Ahmed et al., 2011); as the process of continual internal dialogue and critical self-evaluation of the researcher’s positionality, as well as active acknowledgement and explicit recognition that this position affects the research process and outcomes, it is thereby commonly viewed as the process of continual internal dialogue and critical self-evaluation of the researcher’s positionality, as well as active acknowledgement and explicit recognition that this position may affect the research process and outcome (Bradbury-Jones, 2007). Reflexivity is self-appraisal in research: it means turning the researcher’s lens back onto oneself to recognise and take responsibility for one’s situatedness within the research and the effect that this may have on the setting and people being studied, the questions being asked, the data being collected, and its interpretation. As such, the idea of reflexivity challenges the view of knowledge production as independent of the researcher producing it and of knowledge as objective.

Relevant aspects of the researcher’s positioning include personal characteristics, such as gender, skin colour, affiliation, age, sexual orientation, immigration status, personal experiences, linguistic tradition, beliefs, biases, preferences, theoretical, political and ideological stances, and emotional responses to participants (Hamzeh & Oliver, 2010). These positions of the researcher may impact the research in three significant ways. First, they can affect access to the ‘field’ because respondents may be more willing to share their experiences with a researcher they perceive as being sympathetic to their situation. The researcher may, in addition, be more knowledgeable about potentially helpful and informative resources. Second, such aspects of positionality may shape the nature of the researcher–researched relationship, which will, in turn, affect the information that participants are willing to share; thus, a woman may feel more comfortable discussing sexual experiences with another woman than with a man. Finally, the worldview and background of the researcher affects the way in which they construct the world, use language, pose questions, and choose the lens(es) for filtering the information gathered from participants and making meaning of it; thus, the researcher’s background may shape the findings and conclusions of the study.

Within this subsection, I reflect on my own positionality as a researcher conducting research in an unfamiliar context in my home country. For my PhD, I critically explored mycetoma disease across different levels. During this period, I shifted from being a doctor working in a biomedical centre, to being a PhD researcher in the field of medical anthropology. Moreover, I relocated across three different places: my original home in Khartoum, to Sennar where I did my fieldwork, and to the United Kingdom, where I received some of my training.

From ‘others’ to ‘friends’ and everything in between: my experience of living in the United Kingdom

Early on in my PhD, I relocated to the United Kingdom (UK), where I received one-to-one training from my lead supervisor Professor Zaman. A part of this training involved my living with an English family to observe their daily activity, and to reflect on my experience in moving from my comfortable life in Sudan to a new place where I was considered an outsider and potentially a member of a marginalised group as a black African Muslim.

It was clear to me from the very beginning that wherever I went, there were preconceived notions about who I was. “A man from an Arab country?” “An Islamic resident in our home?” Unspoken, but loud. I felt that unvoiced opinions were screaming around me. Whether negative, positive, or merely “of interest”, I was not in a country that saw me as a blank slate.

Aside from features, traits, and the colour of my skin, there were more subtle differences between my culture and the one that I found myself living in. I was a socially inclined man, with communal values, who was used to giving before receiving, and serving others’ needs before my own. This was seemingly uncommon in the individualistic environment I found in the UK. Privacy was a pillar of society, along with sensible subtle communication.

As my work unfolded, and with more trips to the UK, I found myself living with couples of different racial backgrounds, who showed varying levels of friendliness and willingness to interact with me. However, I found there to be some binding commonalities across the families: the individualism was always there, except that it was sometimes a ‘default’ that could be changed, and was at other times a shield people used to keep their distance from me. Despite our social, cultural, intellectual, racial, ideological, lingual, religious, and gender differences, mutual respect was ultimately the thread that wove us closer together. After months of interactions, I am now happy to call many of my hosts in this foreign land – friends.

Painfully parallel: the research bubble at the Mycetoma Research Center (MRC)

By the time I joined the MRC I was established professionally and personally as a PhD student and a physician. At that time, I also worked with the Ministry of Higher Education and Scientific Research in the IT service team, coping with the hardships of re-establishing my credentials and financial and social status. I was considered an outsider, not only as the first researcher conducting social science research in this purely biomedical research centre, but also as the only PhD student supported by the NIHR fund who did not have experience at this centre.

Anthropology is an unknown discipline at the MRC and requires a different methodological approach compared with the biomedical field that the staff there are used to. Anthropological research does not generate the same prompt, quantitative data outputs as epidemiology or laboratory research. Studies take much longer to complete before research is written up for publication, often as a book chapter or monograph. In general, the social science disciplines are broadly under-represented in Sudan. For example, neither the department of Global Health and Infection in Brighton nor the MRC were able to identify a suitably trained anthropologist in Sudan to provide local expert supervision. Professor Shahaduz Zaman, Dr Mei Trueba, Dr Victoria Hall, and Dr Caroline Ackley are all anthropologists who have provided PhD support and supervision at Brighton and Sussex Medical School. Professor Fahal – a professor of surgery and the director of the MRC – acted as my local supervisor. He supported me by providing broader post-graduate training guidance in the context of mycetoma. He welcomed the idea of having social science research in the centre, but it was challenging for him to approve the anthropological method of collecting data (not in a lab, but by talking with people in the community). Concerns were raised about my attendance at the MRC clinic, and I ended up working outside the centre in an environment where I felt more able to study.

The director of the MRC, my second PhD supervisor, found it difficult to distinguish such ‘anthropology life’ from biomedical research. It is also likely that the ethics committee found it difficult to distinguish what ‘they’ do from what ‘we’ do. But, hopefully, over time, they will also learn to view these hitherto exclusively ‘social’ research areas through a biomedical lens. They will increasingly require anthropologists and other social scientist researchers to face the more restrictive ethical protocols that pertain to biomedical research. Chenhall et al. (2011) suggest better training in qualitative research methods for members of ethics committees, and argue that through a focus on ethics in practice researchers can work to deepen our understanding of ethics in ethnographic research (Chenhall et al., 2011).

Before undertaking qualitative research training, I was a practising doctor in the centre and regularly attended the clinic to treat patients. There was resistance from the centre director to the idea of changing this during my PhD fieldwork. He requested that I make the MRC my main place of work to ensure my full integration into the MRC research team. There was a lot of interest in anthropology research among my peers. We agreed that I could contribute to the group through sharing learning and adding a new dimension to ongoing biomedical research, and could work while pursuing my own anthropological research. The centre director also requested that I continue with my clinical work, which was not a part of the initial PhD agreement.

I worked as a doctor in the MRC on Mondays, trying to make the most of this by making in-clinic observations and documenting them. I also tried to conduct some participatory research with some of my patients, while also reflecting on my experience as a physician regarding the way in which we treated mycetoma patients. Working as a physician who was treating more than 50 patients per day, I was more likely to pay attention to the wound exclusively: I saw more than 50 feet, more than 50 mycetoma ‘cases’, rather than seeing more than 50 individuals affected by the disease. So I started to pay attention to these significant differences – between myself as a physician before entering the field of medical anthropology, and myself as a medical anthropologist practising medicine.

I started to carry out some interviews while in the clinic; I even did participatory action research via small group discussions with these individuals, and dedicated time to conducting my observation in the waiting area at the centre. When considering the location of the interview, and the power imposed on the individuals concerned, it can be seen that the result(s) of these observations was very much influenced by the context. An important finding triggered me into seeking more information in a naturally occurring setting: as such, I began to meet some of my mycetoma patients outside of the MRC. Nevertheless, my positionality as a physician affected the data, leaving me only to do my ethnography in a highly endemic area, but on its natural occurring setting.

Sharing my experience at the MRC with study participants positioned me in the role of the ‘insider’. As such, this offered the three advantages that were discussed by Padgett (2015) and Kacen and Chaitin (2015) in studying the familiar: a more accessible entrée, being ahead from the start in terms of knowledge about the topic, and understanding the nuanced reactions of participants. In addition, my own experiences within various cultural locations provided insight into the culture, as has also been illustrated by the experiences reported by Ahmed et al. (2011) in their study of visually impaired young people in Bahrain.

The Covid-19 pandemic: research, community, and global ‘norms’ shaken and questioned

In March 2020, the World Health Organization (WHO) director-general commenced an emergency committee meeting to discuss the issues from 22–23 January 2020. Still, it was not until 30 January 2020 that the WHO declared the Covid-19 outbreak as a public health emergency of international concern, and issued guidelines to countries. Later, on 11 March 2020, the WHO officially announced the outbreak to be a global pandemic – the first in centuries. Subsequently, the first case reported in Sudan was on 13 March 2020. Two days later, the government announced the closure of all schools and universities. A state of national health emergency was declared on 16 March, prompting a halt to social interactions. On 24 March, the government announced a partial curfew in Khartoum State, and, lastly, the total lockdown of Khartoum State was announced on 13 April 2020. With most of the country living on or around the poverty line, this raised significant concerns for people’s livelihoods (Osman et al., 2021).

This lockdown led directly to the postponing of my ethnography and fieldwork in Sennar State. Although the fieldwork had previously been planned to start in April 2020, I instead stayed at home and worked on my thesis chapters under the guidance of my supervisors. The most challenging part of the last year was the Covid-19 pandemic, not only in the delaying of the fieldwork and ethnography, but also in the broader context of my identity, as the older brother and the certified medical doctor in my area. The Covid-19 situation also affected my mental health, especially in the early months, prompting anxiety and stress that were completely unfamiliar.

This was a period full of uncertainty and concerns; I was unsure as to whether I would be able to continue with my PhD or whether the funding would cease. These concerns grew substantially when the disease hit Sudan. It became a matter of whether one would survive this pandemic or not; at the start of the pandemic my mother began to show the symptoms of Covid – this sentence spoke to my deepest fears. Although I myself experienced the disease later with more severe symptoms and a very rapid progression, and I was diagnosed with lung metastasis, somehow this seemed minor compared with the threat to my mother’s life. Even as I lay in an ICU bed, with an unknown prognosis, I was relieved that my family was okay. I was the caregiver more than a healthcare provider or a doctor in this particular situation. I sincerely appreciate the generous help and support of my supervisors, Dr Zaman and Dr Mei Trueba, during these difficult times, as well as the reassurance and support received from the head of the department, Prof. Newport.

Hierarchies in anthropological research: impressions through networking events

Despite north–south and south–south knowledge exchange and research leadership, global research into infectious diseases – including NTDs – has been increasingly decolonised. This was clear in the diversity of conferences focusing on mycetoma that I attended during the course of my PhD, not only in the sense of an increase in different-coloured attendees (a traditionally tokenist gesture), but also because of the increase in the number of independent researchers and principal investigators from LMICs since the start of my PhD in 2018. I see this phenomenon as a fundamental – and necessary – shift in power from locals being seen as mere ‘data collectors’ to their being leading partners that drive strategic priorities.

There is still more to be done. Funding into mycetoma and its research in Sudan still comes only from international sources, not from local ones. This in itself limits the donor perception of which opinions count, of with whom the local/traditional knowledge is stored, and of who the unheard populations are. I also need to emphasise the built-in barriers against the inclusion of such communities:

> *a) An unnecessarily high level of language elitism.* Even as a highly educated Sudanese citizen, I have found the level of English, its literature, and ‘common’ phrasing to be at times unnecessarily complex. As a field focused on breaking down social injustices, medical anthropology networks should account for lingual diversity. I have attended more than seven conferences focused on mycetoma, none of which had a single translator. I found this to be quite disappointing. An infected Arabic-speaking person in Wad Elnimear village may know more about mycetoma than do many conference attendees, but they would be dismissed because they simply did not speak the ‘right’ language. This is then reflected in the knowledge collected, the conclusions extracted, and the later-published (English) papers. I personally believe, subsequent to my specific research, that accessibility to translators could be the first step to breaking the barrier of language elitism.
>
> *b) An intellectual niche.* There is a background to anthropological research that many do not have access to. Even just looking at the literature that I have included in this research, the evidence goes back decades. While many pride themselves on open-access

articles, there remain structural impedances to accessing this information – lack of electricity and internet, limited education outlets, and inaccessibility without a VPN. There are also internalised barriers, such as a lack of awareness that this information exists. In the context of this research, Sudanese researchers such as myself have been placed at a slight disadvantage. While it has been challenging to catch up, I still consider myself to be in a fortunate position – having previously been a medical doctor, I was already acquainted with the medical basics of the disease. I had this knowledge – but many of my peers did not.

c) Questions asked, but addressed to the wrong people. Throughout my data collection, I became increasingly aware of the lack of community inclusion in programmes, interventions, and services. I met people who had courageous and revolutionary perspectives on mycetoma, but was surprised to find out that I was the first person to have asked them any questions about the illness and their experience of it. Beyond research, people leading policy and practice should acknowledge that the most important perspectives are often ‘invisible’. Intellect is not homogenous, but exists in different forms. In order to break down the barriers to involving those who are affected the most by mycetoma, we need to first recognise the true value of their knowledge and the wealth of information that it can contribute to controlling the illness.

d) Access (and lack of access) to international borders. We are governed by artificially drawn national borders with very real consequences on research and its equity. I found visas and the ‘filtration’ exerted by borders – which exclude people like me – to be frustrating. Why was I refused a visa for a conference on a subject in which I am considered a leading researcher? Were my colleagues accepted – and, if so, what were their racial backgrounds? Medical anthropology is not immune to the inequalities of the world, and I hope that diversity and inclusion become a more prominent focus in the next generation of mycetoma research. It is important that it is not only people with special passports that speak out, but that all of us have a voice as a united front.

As for many others, my PhD journey has not been easy. I experienced a tremendous number of challenges and obstacles across different levels: being a physician shifting from direct medical care to the field of anthropology, conducting research and writing an entire thesis in a foreign language, the global pandemic, being personally affected by Covid-19, and being based in a biomedical research centre that was not yet familiar with qualitative research, among other factors, all made the journey extremely difficult at times.

In the following chapters I address some of my PhD findings, starting with my first visit to one of the areas where mycetoma is highly endemic – Wad Elnimear village – where I investigated the failure of a particular health intervention: that of the artificial animal enclosure project.

Chapter Three

Mycetoma, a Neglected Tropical Disease

Chapter Three: Mycetoma, a Neglected Tropical Disease

Neglected tropical diseases (NTDs)

While the main focus of this thesis is mycetoma, I start this section by introducing the history and epidemiology of neglected tropical diseases (NTDs). I then dive into the global burden of NTDs, before highlighting the sociocultural, political, and health system aspects around NTDS. Following this, the chapter continues to examine mycetoma, focusing specifically on the important milestones of the disease across history, the burden of it globally and locally, and clinical considerations around the disease, before closing off with the social aspects of mycetoma.

Neglected tropical diseases are a group of 20 diseases caused by different pathogens. Together, they affect more than 1 million people living in tropical and subtropical regions (WHO, 2022c). These diseases have been historically overlooked at the community, national, and international levels (Mackey et al., 2014). However, over the last decade, there has been a spike in global awareness around NTDs after their inclusion in the Sustainable Development Goals (SDGs). Despite being non-specifically grouped under ‘other diseases’ in the previous Millenium Development Goals (MDGs) under goal number six (see WHO, 2022a), they have been proactively incorporated within the SDGs. Their inclusion comes as a big success for the relentless advocacy efforts; however, they remain in the shadow of the comparatively well-funded ‘big three’ – tuberculosis, malaria, and HIV/AIDS – receiving a disproportionately small share of health funding and research attention relative to their disease burden (Hotez, 2020; Shahvisi, 2019). NTDs became the core focus of the newly established Department of Control of Neglected Tropical Diseases by the WHO in 2005 (Parker et al., 2016). The initial NTDs list consisted of 13 chronic and debilitating infections, most of which were parasitic diseases (Hotez, 2020). The list included three soil-transmitted helminthiases (namely: ascariasis, hookworm infection, and trichuriasis), lymphatic filariasis, onchocerciasis, dracunculiasis, schistosomiasis, Chagas disease, human African trypanosomiasis (HAT), leishmaniasis, Buruli ulcer, leprosy, and trachoma (Conteh et al., 2010). NTDs then became a popular category which has spawned an established area of scholarship and elicited a more substantial, yet still inadequate, public health response. The term itself reflects the advocacy work behind it; ‘neglected’ was aimed at drawing the attention of donors and policymakers into acknowledging the urgency of the problem; while ‘tropical’ was intended to indicate the regions in which these diseases prevail. They are primarily diseases of the ‘bottom billion’, the poorest one-sixth of the world’s population, among whom they cause massive suffering through acute illness, long-term disability, and early death. All low-income countries are affected by at least five NTDs, and many individuals who live in these countries are concurrently infected by more than one pathogen (Feasey et al., 2010). This affects the magnitude of health loss due to diseases and injuries, as disability-adjusted life-years (DALYs), which decreased by 29·7 per cent between 2007 and 2017 as reported by Kyu et al. (2018).

Later, the WHO expanded the 2005 list to include conditions they considered to be of global public health importance. In May 2013, the 66th World Health Assembly (WHA) resolved to intensify and integrate measures against NTDs, and also to invest in the improvement of the health and social wellbeing of affected populations. In 2016, the 69th WHA adopted a resolution proposed by the Sudanese Ministry of Health on addressing the burden of mycetoma (Van De Sande et al., 2018). Among the helminth infections, they added echinococcosis, foodborne trematodes, and taeniasis/cysticercosis. Chagas disease was added to the protozoan infections list, while yaws (endemic treponematoses) was added to the list of bacterial infections. In addition, a group of deep fungal mycoses was added. Viral infections were not in the original listings, but the WHO added two arbovirus infections, dengue and chikungunya, as well as rabies. Furthermore, the WHO added scabies and other ectoparasites, in addition to snakebite envenomation; currently, the WHO identifies 20 major conditions as NTDs (Hotez, 2020).

Unlike conventional disease classifications, NTDs have no scientific basis in common. Rather, they are defined operationally on the basis of the apparent commonality of their spatial epidemiology and their mutual marginalisation in terms of research and funding. This is evident in the definition given by the WHO, which recognises the broad diversity of NTDs in terms of conventional medical taxonomy, yet their concurrent similarity in terms of social determinants (Shahvisi, 2019). NTDs are subsequently characterised by the following important elements: the most common infections of people living in sub-Saharan Africa, Asia, Latin America, and the Caribbean where poverty is common and/or endemic.

The WHO prioritises 20 NTDs, while a Public Library of Science journal dedicated to NTDs lists almost 40 such diseases. There are many under-researched and underfunded diseases concentrated in ‘tropical’ world regions (Shahvisi, 2019). All of these diseases, to a greater or lesser extent, have been neglected by funders, researchers, and policymakers.

The global burden of NTDs

With the exception of some arboviral infections and rabies, NTDs are generally described as chronic, debilitating, and disfiguring conditions that occur most commonly in the setting of extreme poverty (Alvar et al., 2006). They can negatively affect productivity, child development, societal stigma, and the health of women (Hotez & Kamath, 2009), and are especially frequent among the rural poor and some disadvantaged urban populations, particularly in sub-Saharan Africa (Hotez, 2020; Hotez & Kamath, 2009).

NTDs affect about 1.4 billion people who live below the World Bank’s poverty figure of US$1.25 per day (Choffnes & Relman, 2011) They can result in chronic infections lasting years or even decades, subsequently leading to a significant negative impact on the family revenue of those affected. The chronicity of the NTDs affects children’s growth and their intellectual and cognitive development, impairs pregnancy outcomes, and decreases workers’ productivity, resulting in billions of affected people who cannot escape poverty (Choffnes & Relman, 2011). Among these consequences, NTDs can also cause blindness and disfigurement that are psychologically devastating and result in social stigma. This high level of morbidity, economic impairment, and stigma does not necessarily translate into large numbers of deaths; overall, the NTDs cause high-morbidity, but low-mortality conditions (Choffnes et al., 2011; Hotez, 2020).

NTDs affect more than 149 countries in the tropical and subtropical regions, and contribute to nearly 19 million DALYs, that is, about 1 per cent of the global burden of disease. It is estimated that more than 1.7 billion people require treatment for at least one NTD every year (WHO, 2022b). NTDs cost the governments of lower- and middle-income countries billions of dollars every year (Choffnes & Relman, 2011). Populations that are living in poverty, without adequate sanitation, and in close contact with infectious vectors, domestic animals, and livestock, are those worst affected (WHO, 2019). Around 1.5 billion people have soil-transmitted helminth infections, that is, 24 per cent of the world’s population. Additionally, over 267 million preschool-age children and over 568 million school-age children live in areas where these parasites are intensively transmitted (Jourdan et al., 2018).

NTDs that are highly prevalent in Sudan are schistosomiasis, lymphatic filariasis, and leishmaniasis. Schistosomiasis affects almost 240 million people worldwide, and more than 700 million people live in endemic areas (Gunda et al., 2020). Lymphatic filariasis affects more than 120 million people in tropical and subtropical regions (Bagcchi, 2015) and has a significant social and economic impact, with an estimated subsequent annual loss of

US$1 billion, and the impairing of economic activity up to 88 per cent (Hotez & Kamath, 2009). Leishmaniasis is endemic in 88 countries, with more than 350 million people at risk. The estimated incidence is 2 million new cases per year (Alvar et al., 2006). According to WHO official reports received from 138 countries, the global registered prevalence of leprosy at the end of 2015 was 176,176 cases. The number of new cases reported globally in 2015 was 211,973. The number of new cases indicates the degree of continued transmission of infection. Global statistics show that 199,992 (94 per cent) of new leprosy cases were reported from 14 countries, in other words, these countries were reporting more than 1,000 new cases each, and only 6 per cent of new cases were reported from the rest of the world. Pockets of high endemicity can still be found in some areas of many countries, including countries reporting fewer than 1,000 new cases. Some of these areas show very high notification rates for new cases, and may still witness heavy transmission (WHO, 2020). NTDs remain endemic in 13 low- and middle-income countries worldwide (Alvar et al., 2006).

Mycetoma commonly affects young adults, particularly males aged between 20 and 40 years (Fahal, 2004), and also mostly those within low- and middle-income countries. People of low socio-economic status and manual workers, such as agriculturalists, labourers, and herdsmen, are the most commonly and worst affected (Van de Sande, 2013). Mycetoma has numerous adverse medical, health, and socio-economic impacts on individuals, communities, and health authorities. As mycetoma is a badly neglected disease, the funding streams that support it are limited; accordingly, accurate data on its global incidence and prevalence are not currently available (Van de Sande, 2013).

Stigma and NTDs

Most people with NTDs are prone to social stigmatisation and discrimination, due to the physical impairments and disfigurements that accompany some of these diseases (Hofstraat & Van Brakel, 2015a; Psychology, Kuper & Lindley, 2019). Leprosy, for instance, is a major NTD that has attracted health-related stigma studies (Weiss, 2008). In one of the early works regarding health-related stigma, Kellersberger, in 1951, described the mistreatment of people with leprosy, highlighting the misinformation that sparked fear of the disease, and the tension between sensationalistic press accounts and efforts to promote responsible legislation (Kellersberger, 1951.). In 1963, Goffman reconceptualised stigma with reference to social interaction(s), and subsequently defined stigma as a damaging social label or attribute that taints or discredits the person, influences social interactions, and jeopardises opportunities for social inclusion (Goffman, 1963). Later, Weiss claimed that Goffman's interest in stigma was mainly from the academic and social-theory point of view, rather than in terms of social policy and/or health policy (Weiss, 2008). Weiss defined health-related stigma as a social process, which is either experienced or anticipated, and is characterised by exclusion, rejection, blame, or devaluation, and results either from experiences or from reasonable anticipation of an adverse social judgement about a person or group (Weiss et al., 2006). Similarly, Van Brakel identified five categories of health-related stigma, including: the experience of actual discrimination (enacted stigma); attitudes towards affected people; perceived or felt stigma; self or internalised stigma; and discriminatory practices in health services (Van Brakel, 2006). 'Enacted' stigma can be described as the negative attitudes expressed by the community, while 'anticipated' stigma is the perception of the individual that stigmatisation is likely to occur. In the case of 'internalised' stigma, the affected individual has internalised negative stereotypes or negative attitudes, may then feel ashamed or guilty because of their condition, and may subsequently withdraw themselves from social participation (Hofstraat & Van Brakel, 2015a).

Health-related stigma (of all categories) is linked to most of the NTDs. Two NTDs, leprosy and syphilis, are among the first described as 'repulsive' (Ribera et al., 2009). Stigma has also been associated with hematuria in urinary schistosomiasis (Takougang et al., 2004), lesions of onchocercal skin disease (Brieger et al., 1998), and scabies (Heukelbach & Feldmeier, 2006). In lymphedema-related stigma, resultant experiences of stigma are similar to enacted, perceived, and internalised stigma drawn from the literature (Person et al., 2009). In cases of podoconisis, the findings suggest that felt stigma is more prevalent than enacted stigma in a study done in Ethiopia, where the disease is predominantly reported (Deribe et al., 2013a). In terms of leishmania, subsequent stigma is found to be associated with post-kala-azar dermal leishmaniasis, which leads to further delay in health-seeking behaviour (Garapati et al., 2018). Stigma is associated not only with the individuals affected by the disease, but also with their surrounding community members, and even healthcare providers (Yakob et al., 2010). This stigma can also serve as a barrier between affected individuals and health intervention and participation in research (Deribe et al., 2013a). Such stigma can impact individuals to the extent that some of the affected patients have thought of ending their lives (Tora et al., 2014).

The health system around NTDs

Despite advancements in the combatting of NTDs, the current resources and global political commitments are insufficient (Liese & Schubert, 2009). This section examines the global response to NTDs, focusing especially on the health system factors of: leadership and governance, health finance, human resources for health, health information systems, service delivery, and medicines and supply chains.

Governance and leadership

The heterogeneity of control initiatives of NTDs persists, despite the similarities across that group and early calls for integration. A close examination of NTDs in various countries shows some differences in terms of origins, geographic coverage, epidemiological goals, stakeholders involved, funding, and governance structures (Liese & Schubert, 2009). Despite their importance and relevance to several developing countries, NTDs were not included in the list of MDGs, but were later added to the list of SDGs. This inclusion was along with that of: HIV/AIDS, tuberculosis, malaria, hepatitis, water-borne diseases, and other communicable diseases, as part of a goal to end epidemics by 2030 (Vanderslott, 2019).

The WHO retains a central role in the leadership and the guiding of NTDs programming globally. The high-level strategic vision for the work of the WHO for the period 2014–2019 included the eradication or elimination of selected NTDs (lymphatic filariasis, schistosomiasis, and soil-transmitted helminthiasis, through regular anthelmintic preventive chemotherapy). Furthermore, there are regional initiatives leading efforts towards a particular NTD. For example, the African Programme for Onchocerciasis Control (APOC) is a regional initiative that included several African countries (WHO, 2015). However, the prioritisation of NTDs is relatively lower at the country level, in contrast with that of many other global health issues (Iltis & Matthews, 2017).

Health finance

Cost effectiveness is a key feature and a benefit in numerous NTD interventions, yet NTDs have been relatively ignored on the global health policy agenda (Liese et al., 2010). A report by NTD partners highlighted that US$200 million per year, on average, is needed to meet the 2020 roadmap targets. There is a shortfall in the finance of the research and development of therapeutics, diagnostics, and preventive measures for NTDs (Benazzouz et al., 2021). While the international aid that was dedicated to NTDs between 2010 and 2020 has driven progress to control and eliminate NTDs, domestic financing will be critical to sustaining NTD control and elimination programmes over the next decade (Huang et al., 2021). Furthermore, using national health accounts to track domestic resources dedicated towards NTDs could be considered a crucial first step in highlighting the importance of NTDs in the allocation of health resources within particular countries.

Welburn and his colleagues (Welburn et al., 2016) conducted a study about the impact of financing specific interventions on a single NTD; this showed that interventions could have a high upfront cost, but that once these interventions were effective, the cash then needed for these interventions could decrease dramatically. As an example of this, HAT, caused by T. b. Rhodesiense, is burdensome in Uganda (an infection of animals that occasionally spills over to humans). Interventions have been modelled in areas where cattle are present, and have included the mass administration of drugs targeted to kill Trypanosoma, followed up by the use of routine insecticides to protect cattle against tsetse flies. Such interventions contribute to the health and productivity of both humans and animals, and thus contribute to the overall livelihoods of people. Such interventions have encouraged donors to allocate increasing resources to the development of more cost-effective interventions, and to measure the impacts of existing ones (Welburn et al., 2016).

Health information systems

The provision of better information is a cornerstone in reducing the burden of NTDs. Decisions about public health problems require an efficient and functioning health information system that is able to provide timely and accurate information. In the management of NTDs, information systems should target the building of stronger surveillance and early warning systems for diseases, as well as for cross-cutting issues (such as socio-economic status and climate change) (Whittaker et al., 2013). For example, an integration of NTD control activities in Mali brought numerous gains, including the increased availability of NTD treatment coverage data and the utilisation of census data for purposes that were useful other than for NTD control. However, in contrast to such integration, in Sudan it acted independently creating parallel monitoring and evaluation systems (Cavalli et al., 2010).

Health workforce

In general, there is a global shortage of human resources for health (HRH); for example, the global shortfall of health workers is expected to reach 18 million by 2030 (WHO, 2016). This shortage affects developing countries more than it does developed countries, and these countries also have a higher burden of NTDs. Furthermore, the health workforce in LMICs face additional challenges, such as brain drain and lack of supportive commodities (Cometto et al., 2013).

A study was conducted in Nigeria examining the mass administration of medicines (MAM), where an intervention aiming to eliminate NTDs highlighted several problems facing frontline HRH workers who work on NTDs. First, there was a lack of technical support (in terms of training, supervision, human resource management and workload, equipment and resources, and timing of MAM implementation). The second issue was related to social support and acceptance of interventions by communities and community leaders. The third challenge to HRH in NTD-afflicted areas concerned incentives, both financial, in terms of monetary remuneration, and non-financial, regarding community feedback and recognition (Oluwole et al., 2019).

Medical products, vaccines, and technologies

Medical products are key to any health system and most health system interventions, and particularly so in terms of health system responses to the increased burden of NTDs. The key actors here include international non-governmental actors (such as the WHO and GAVI), large multinational pharmaceutical companies, and national or subnational health systems managers. There have been multiple developments in the fields of vaccines, drugs, and diagnostics. Yet, key challenges to these developments also include: insufficient development efforts, slow responses from GAVI and the WHO in the adoption and promotion of vaccines for NTDs, and the lack of engagement of the major multinational pharmaceutical companies (Hotez et al., 2016). Furthermore, such lack of engagement by these companies could also be explained by the absence of economic incentives for new products relating to NTDs (Bethony et al., 2011), which could be due to several potential market failures. Additionally, these companies are also reluctant to invest in the research and development of products for NTDs, mainly due to the reduced ability of health insurance systems and of potential consumers to pay for such services (Aerts et al., 2017).

In summary, NTDs have a global burden beyond tropical areas. I have highlighted how there has been an increase in awareness and policy actions towards NTDs, and how they have begun to hold a place in the global health arena. I presented the inclusion of NTDs on the actions of the SDGs after having been previously neglected under the MDGs. Furthermore, the WHO has expanded the list of NTDs to include other (neglected) diseases, such as mycetoma. NTDs present a substantial challenge to health systems globally; the integration of NTD programmes with general health services could present a solution to some of these challenges. In the following section, I focus on mycetoma as one of the NTDs.

The foundation of the Mycetoma Research Center (MRC)

In the early 1990s, the landscape of mycetoma treatment was substantially different from what it is today. This remarkable evolution can be traced back to the establishment of a modest mycetoma clinic in 1991 at the Soba University Hospital in Khartoum, Sudan. Fuelled purely by personal commitment, and void of any external support, this small-scale clinic played a critical role in the historical journey of mycetoma treatment.

Initially, this clinic was essentially a surgical unit operating within the Soba teaching hospital. This was largely because, at the time, the University of Khartoum's Faculty of Medicine, the top medical school in Sudan's medical academia from then till now, had a pivotal role in assigning specialised doctors to various specialties. Given the limited number of doctors and resources, in addition to other factors such as the limited available knowledge of the causation in mycetoma, surgery was the frontline and the primary approach to mycetoma treatment.

Over the next two decades, this modest clinic evolved into a dedicated institution, the Mycetoma Research Center (MRC), operating under the University of Khartoum. This transition marked an important shift in the fight against mycetoma, underlining a move from a largely surgical approach to a more pharmaceutical one. One pivotal moment in this evolution was in 2015, when the MRC was recognised as the WHO Collaborating Centre on Mycetoma and Skin NTDs. This significantly bolstered its standing and impact within the global medical community. Despite the historical surgical orientation of the MRC, attributed to the surgical background of its founding members and the then prevalence of surgery in treating mycetoma, the centre began to incorporate a greater proportion of pharmaceutical treatments.

Recently, with the collaboration of the Drugs for Neglected Diseases Initiative (DNDi), the MRC has begun conducting the first randomised clinical trial for a new pharmaceutical drug to treat mycetoma patients. This endeavour further underscores the transition from surgical to pharmaceutical treatment. Although itraconazole is a recognised treatment, the introduction of fosravuconazole marked a turning point in the treatment of mycetoma. This shift towards pharmacological treatments represents a breakthrough in the management of the disease (Van De Sande et al., 2018).

According to its website, the MRC is the locus of much innovative research, having published over 230 articles so far, and collaborated with 16 international partners (MRC, 2022). It also acts as a worldwide referral centre, consequently treating patients from Sudan, Ethiopia, Somalia, Yemen, Saudi Arabia, Chad, Bangladesh, India, Kenya, and the US.

Before 2013, mycetoma was among the most neglected conditions in the field of tropical medicine (Van de Sande et al., 2017). Worldwide, only a few centres reported research data, and that was mainly on the basic science of mycetoma. However, in 2012 in Mexico, a report was published that registered 3,933 cases in the past 54 years (López-Martínez et al., 2013). Most clinical studies addressing treatment were restricted to case reports or small case series, leaving many unresolved issues.

A landmark meeting was held on 1 February 2013 in Geneva, by the DNDi, so as to identify knowledge gaps and research priorities. During this meeting it became evident that there was a lack of proper data on the incidence, prevalence, and mapping of mycetoma, and also on the mode of transmission (Van de Sande et al., 2017). Furthermore, there were no official prevalence and incidence numbers on the occurrence of mycetoma globally or in Sudan; subsequently, an effort was made in 2013 to obtain a rough estimation of the global burden of mycetoma by conducting a meta-analysis of cases published in the literature (Van de Sande, 2013b). To date, however, mycetoma is not a notifiable or reportable disease. Furthermore, there is no proper disease surveillance system, especially in Sudan. Thus, most of the reported cases are limited to anecdotal case reports and passive case detection (Bakhiet et al., 2018a).

The history of mycetoma

There are numerous sources of knowledge that document the history of mycetoma disease, ranging from ancient literature, paleopathology, archaeological findings, and experts. These sources rarely include precise descriptions of the disease, since they tap into the oral traditions of communication that often use the mediums either of the recitation of poetry, or of the chanting of mantras, and, hence, they are difficult to interpret accurately. However, it has been suggested that mycetoma was known to the writers of the ancient Indian texts (Hay, 2021).

The doctoral thesis of the German traveller and physician Engelbert Kaempfer (1651–1716), given to the University of Leiden in Holland in 1694, contained the first *precise* medical description of a disorder probably resembling mycetoma (Hay, 2021). In 1842, English surgeon Gill described the condition now known as mycetoma in the Indian Army Reports. His successor in this post, Colebrook, is credited with coining the name ‘Madura’s foot’. Later, in 1846, garrison surgeon in Bellary, Godfrey, published a case series in *The Lancet* with four patients, referenced under the title ‘Diseases of the foot not hitherto described’, where he cited the work of Gill and Colebrook (Hay, 2021).

The name ‘mycetoma’ was first mentioned in the opening report of Wellcome Research Laboratories. This report highlighted both that the prevalence of the disease was high for such a rare disease, and the domination of black grains over other types of grains. Mycetoma is then mentioned regularly in subsequent reports of the institute, with illustrations of the pathology of the infection (Hay, 2021).

Milestones in mycetoma’s appreciation by the international and Sudanese communities

February 2013

The DNDi organised the first consultation meeting on: ‘Mycetoma: why is it still neglected?’ – an event that was held in Geneva. The meeting was attended by experts on mycetoma from around the world (Van de Sande et al., 2017). The aim was to review all currently available information, and to identify existing knowledge gaps and research priorities. One of the major outcomes of this meeting was the conclusion that basic epidemiological information was lacking: the exact number of people who were suffering from mycetoma was not known, and there was no knowledge of the prevalence and distribution of the disease. Furthermore, early detection of mycetoma was difficult, while treatment was far from satisfactory for eumycetoma patients. The meeting led to the creation of a working plan and a roadmap, so as to promote advocacy for mycetoma, and, in particular, to work on bridging the knowledge gap in diagnosis and treatment of the disease, and also, to address how to create partnerships to improve access to treatment. The meeting was the start of the mycetoma consortium, a group of mycetoma experts supported by the DNDi to advocate for new treatment and diagnosis methods at the international level (Van de Sande et al., 2014b).

May 2013

Later in the same year, a supplementary meeting was held to coincide with the 66th WHA, also in Geneva. The meeting was attended by ministers of health from endemic countries and mycetoma experts. At this meeting, the NTDs/WHO director announced the inclusion of mycetoma on the ‘Other neglected conditions’ list, and a specific page was dedicated for mycetoma on the NTDs/WHO website. After this meeting, the DNDi issued a press release calling for the formal recognition of mycetoma and for increased funding.

In Washington DC, USA, a symposium on mycetoma was hosted by the American Society of Tropical Medicine and Hygiene, principally for greater advocacy regarding the knowledge gap about the disease. Another meeting was held with the Sudanese American Medical Association, which led to a new memorandum of understanding aimed at improving mycetoma awareness.

May 2014

In the 66th WHA, the MRC, University of Khartoum, was announced as a WHO Collaborating Centre. At the same time, a parallel meeting between the Sudanese mission and delegates from the Neglected Disease Department, together with WHO experts supported by the DNDi, announced a global epidemiological study on mycetoma. The aim of this study was to collect data on the magnitude and burden of the disease, as well as to plan for the control of the disease.

May 2015

This year was recorded as being remarkable for mycetoma disease. During the year, a draft resolution by the Sudanese Federal Ministry of Health was submitted to the assembly secretariat to include mycetoma on the WHO/NTD list. The submission was discussed at the WHO 137th Executive Board meeting in May 2015, and was then referred to the WHO 138th Executive Board meeting in January 2016 for further discussion. The treatment gap in mycetoma was, equally, further discussed at a Mycetoma Symposium, which was held at the European Congress of Tropical Medicine and International Health, located in Switzerland (Fahal, 2021).

Sponsored by the DNDi and Eisai, Japan, this year also witnessed a press release on the proposed, first-ever double-blind clinical trial for mycetoma using fosravuconazole.

A story about mycetoma as a neglected disease, written by two medical students from Canada, was awarded a prize of the Global Health Untold Stories contest, organised through the John Hopkins Bloomberg School of Public Health, and in collaboration with the Consortium of Universities for Global Health. The students donated their winnings to enable a scientific journalist to write a series of articles on the lack of international community awareness and advocacy for mycetoma.

The DNDi included mycetoma in its 2015–2023 business plan, and defined the limits and action-oriented milestones to prioritise its contributions within this disease area.

Following the proposal to discuss mycetoma as an NTD, the WHO 138th Executive Board meeting recommended formulating a mycetoma resolution to the 69th WHA, 2016, pending the NTDs/WHO Strategic and Technical Advisory Group (STAG) deliberations. The Sudanese head of mission addressed the meeting supporting the resolution. The WHO Executive Board recommended a resolution on mycetoma to the WHA (Fahal, 2021). The NTD STAG committee further defined a systematic, technically driven process for the evaluation and potential inclusion of new diseases on the NTDs list; the mycetoma draft resolution was discussed by a subcommittee, and mycetoma was recognised as a suitable candidate under the new process.

May 2016

The 69th WHA adopted the Mycetoma Resolution, and stressed the importance of developing better diagnostic tools and treatments for mycetoma.

March 2017

From 16 countries, more than 35 mycetoma experts from a wide range of fields, including: clinical research, diagnostic tool development, drug discovery/pharmaceuticals, epidemiology, ethics, laboratory research, medical practice, health policy, and programme planning and development, were invited to the Global Mycetoma Working Group, as part of the WHO Geneva Skin NTDs meeting, held in March 2017. This led to the formulation of the Global Mycetoma Working Group (GMWG). The inaugural meeting of the GMWG was held on 11 January 2018.

The aim of the working group was to connect experts and public health practitioners around the world, so as to accelerate mycetoma prevention activities and reduce the impact of mycetoma on patients, healthcare providers, and societies within endemic regions (Traxler et al., 2021) (see Figure 9).

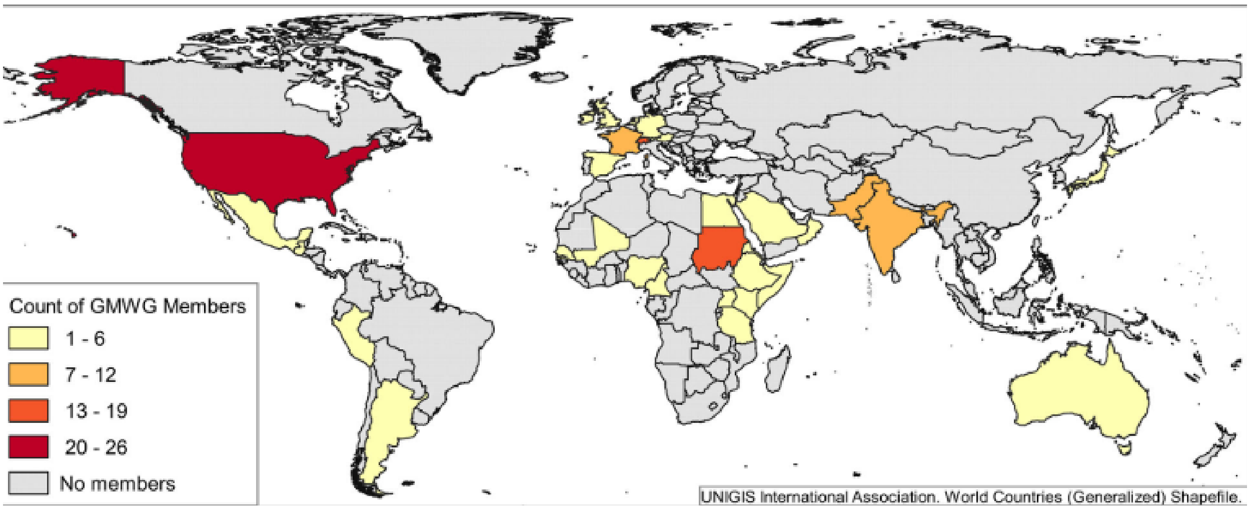

Figure 9: Countries of residence of GMWG members (Traxler et al., 2021).

2018

The WHO visited the MRC. This visit was led by Deputy Director General Dr Soumya Swaminathan on 6 February 2018. She was accompanied by the State Minister of Health, Sudan, and by Dr Neema Al Gasseer, the WHO representative for Sudan, and Head of the Country Office. During the visit, they ensured their active advocacy for operational research, and for their support of the MRC to achieve its objectives and activities (see Figure 10).

On 24 October 2018, the WHO Director-General, Dr Tedros Adhanom Ghebreyesus, visited the MRC as a WHO Collaborating Centre on Mycetoma. He pledged to support MRC initiatives that produced better diagnostics and medicines for mycetoma patients. Dr Ghebreyesus also called for further research into mycetoma, particularly on its epidemiology, and towards diagnostics to produce a simple point-of-care test; he also called for new cost-effective medicines and disease control (MRC, 2018) (see Figure 11).

Figure 10: High level officials from the WHO and MRC (MRC, February, 2018).

Figure 11: Visit of the WHO Director-General, Dr Tedros Adhanom Ghebreyesus, to the MRC as a WHO Collaborating Centre on Mycetoma and Skin NTDs (MRC, October, 2018).

February 2019

The MRC hosted the First International Training Workshop on Mycetoma in Khartoum on 10–14 February 2019, with the collaboration of the Federal Ministry of Health representative and the WHO. Drawing on the expertise of the MRC in Khartoum, the workshop was attended by approximately 70 health staff from many mycetoma-endemic countries. It provided a unique opportunity to share experiences, and to standardise practices relating to diagnosis, treatment, and surveillance.

The workshop was then followed by the Sixth International Conference on Mycetoma in Khartoum on 15–17 February 2019. The conference adopted the ‘Khartoum Call for Action on Mycetoma’, which called upon a wide range of actors to take specific public-health and policy measures to address the burden of mycetoma.

The power of the MRC to draw attention to mycetoma and influence the WHO’s consideration of mycetoma as an NTD indeed exemplifies a form of considerable power. Drawing the attention of a prominent global health organisation such as the WHO requires significant influence, advocacy, and strategic efforts.

On the other hand, the centralised power of the WHO amplified the power of the MRC. The listing of mycetoma as an NTD made it a global health priority. Moreover, channelling resources efficiently, fostering international collaboration, and advocating for neglected diseases, the WHO amplified efforts to combat mycetoma as well as the power of the MRC. This collaboration between the MRC and the centralised entity of the WHO exemplifies how research institutions and global health organisations can synergise their powers.

The incidence and prevalence of mycetoma in Sudan

The main epidemiological statistics of mycetoma remain one of the major knowledge gaps regarding the disease. To date, the exact number of people with mycetoma is not known, and there is no conclusive knowledge of the prevalence and distribution of the disease worldwide. All the available data is based on case reports published in the literature, which are then deployed to obtain a rough estimation of the global burden of mycetoma.

The first documented clinical cases of mycetoma were described in 1842 by Gill, but uncertainty remains about the total number of cases worldwide, as was mentioned by Gokhale in 1981. In 1956, Abbott conducted the first attempt to map the number of mycetoma cases, and his study was carried out in Sudan (Abbott, 1956). Abbott studied 1,321 mycetoma cases in a 2.5-year period, and published his findings in 1956. This ignited other scientists; they were surprised by the number of cases to be retrieved in such a short period of time, which could indicate that the burden of mycetoma was higher than was previously thought. Therefore, other scientists then started to determine the burden of mycetoma in countries where it was known to be endemic, such as Congo, Somalia, Argentina, and Mexico. Although several studies have been performed to determine the prevalence of mycetoma within a certain region or country, to date no overall study has been carried out to determine the prevalence of mycetoma worldwide (Van de Sande, 2013).

In order to estimate the true burden of mycetoma globally, a meta-analysis was performed by Van de Sande and her colleagues in 2013, in which all studies of the epidemiology of mycetoma causative agents were reviewed. The burden of mycetoma was determined in terms of prevalence and the number of reported cases per year, per country. The team also determined which species were most commonly associated with mycetoma, and prepared definitions based on 8,000 cases so as to determine which species were either commonly, occasionally, or rarely associated with mycetoma development. In this meta-analysis, Van de Sande included 50 studies from the existent literature, and, from each of these studies, the number of cases was recorded, alongside the gender of the patients, the age of the patients, the site(s) of the lesion(s), and the causative agents isolated. A total of 8,763 mycetoma cases were included in this study, and most of these cases were reported from three predominant countries: Mexico, Sudan, and India (Van de Sande, 2013) (see Figure 12).

In 2017, Van de Sande again conducted another electronic database search, so as to update the existent data on the burden of mycetoma (Van de Sande et al., 2017). This meta-analysis was performed on 8,763 published cases, and the prevalence of mycetoma was calculated by dividing the number of reported cases by the country population in each year. Data retrieved from the literature search of the studies published in the years 2013–2017 was then added to update the number of cases published in the previous meta-analysis. This then doubled the number of cases recorded to 17,607 cases, and the previously published prevalence map was updated accordingly.

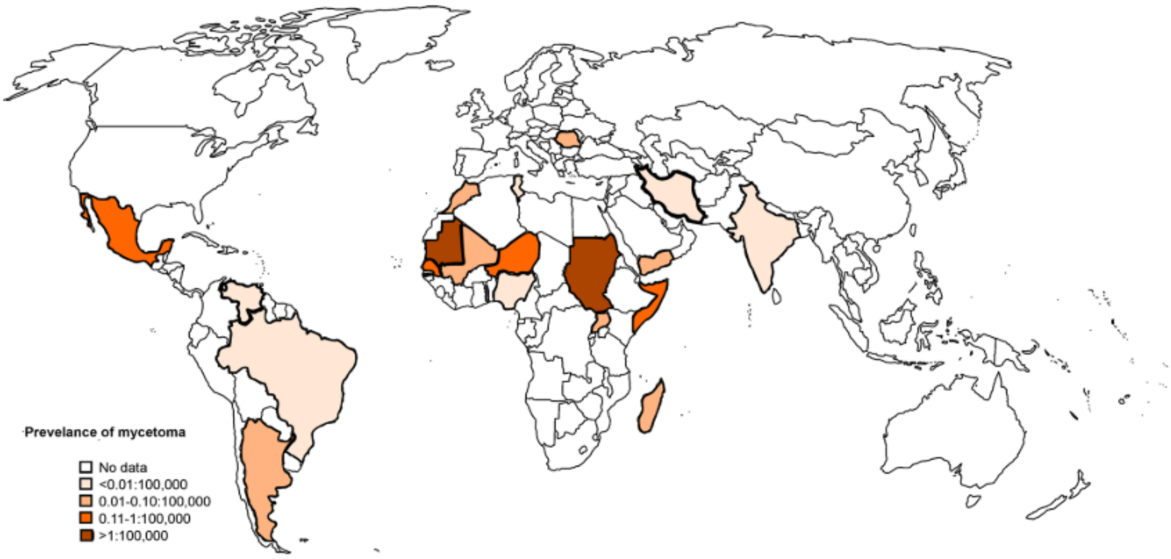

Figure 12: Estimated prevalence of mycetoma (Van de Sande, 2017).

In 2020, Darcy Emery and David Denning from the University of Manchester also published a literature review of mycetoma case reports and case series, drawn from 332 papers in total. Unlike Van de Sande, however, they additionally included languages other than English, French, Italian, and Spanish. Using the Quantum Geographic Information System (QGIS), they then provided maps for the distribution of the disease (see Figure 13). A total of 19,494 mycetoma cases were identified, dating from 1876 to 2019. According to their search, mycetoma had been contracted in 102 countries, many of which were outside the so-called ‘mycetoma belt’; this, therefore, drew attention to the global distribution of the disease outside of tropical and subtropical regions. Sudan remains the homeland of the disease, as the highest number of cases (10,608) were reported from there (Emery & Denning, 2020).

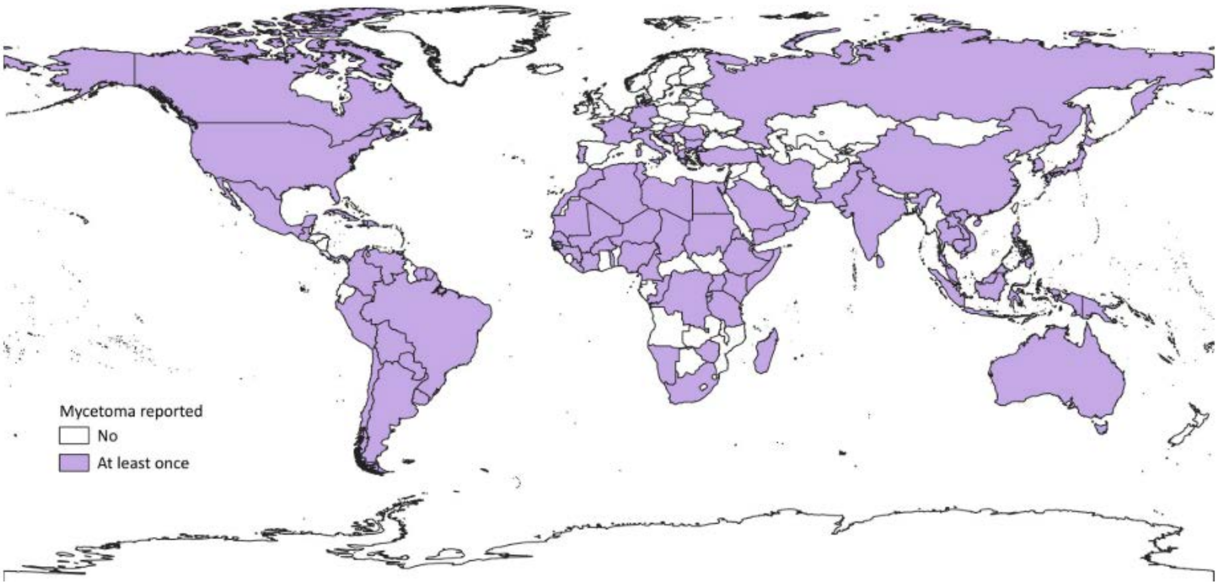

Figure 13: Countries where mycetoma has been reported by Emery and Denning (2020).

Emery and Denning's study provided a larger figure than did previous ones, the last of which, conducted by Van de Sande in 2017, collated 17,607 cases. There may be several reasons for this. First, there are a greater number of recently recorded incidents of mycetoma: 20 countries reported cases in the brief interim between studies, including some registered within Eritrea, Hungary, and Timor Leste, for the first time. Second, unlike Van de Sande's prevalence map, Emery and Denning's representation does not take population size into account. Thus, it subsequently presents a wider distribution, with the incorporation of representation(s) for countries such as Kenya, whose 155 cases were previously hidden by its population size. Emery and Denning studied a greater number of databases, and more languages were included. While Van de Sande's 2013 study calculated the Sudanese prevalence of mycetoma at 1.81 per 100,000 population (with most cases coming from the MRC, located in the capital Khartoum), a study in rural Sudan (Sennar State) found the prevalence to be as high as 0.87 (Hassan et al., 2021a). As mycetoma is associated with rural agricultural practices (Van de Sande et al., 2017), it may be that many cases did not present to large healthcare facilities, and therefore went through different treatment pathways, hence escaping the associative reports and publishing.

On the basis of current information, there is no published prevalence or incidence for the disease in Sudan, and mycetoma is not on the list of notifiable diseases. Furthermore, Sudan lacks a disease surveillance system for mycetoma. As a result, the majority of reported cases are limited to anecdotal case reports and passive case detection (Bakhiet et al., 2018). The burden of the disease is estimated from the number of patients reaching medical and research facilities. The first reported prevalence, as indicated by Abbott in his early studies, was a facility-based prevalence, whereby he studied mycetoma patients from different parts of Sudan and reported 0.51 per cent as the prevalence of mycetoma patients among general hospital patients seen in Khartoum. He described higher prevalence within central Sudanese states (Abbott, 1956).

Several community-based epidemiological studies were also published. In 2014, Fahal and his team conducted a study in a village in White Nile State, Sudan, so as to determine the burden of mycetoma, and reported a prevalence of 1.45 per cent (Fahal et al., 2014).

In 2021, Hassan and her team also published a large survey in Eastern Sennar locality, Sennar State, so as to investigate the disease's epidemiological characteristics (Hassan et al., 2021a). They subsequently reported that a total of 41,176 individuals were surveyed, and that from among these, 359 mycetoma patients were identified. The overall prevalence of mycetoma was 0.87 per cent (95% CI = 0.78–0.97%: see Figure 14).

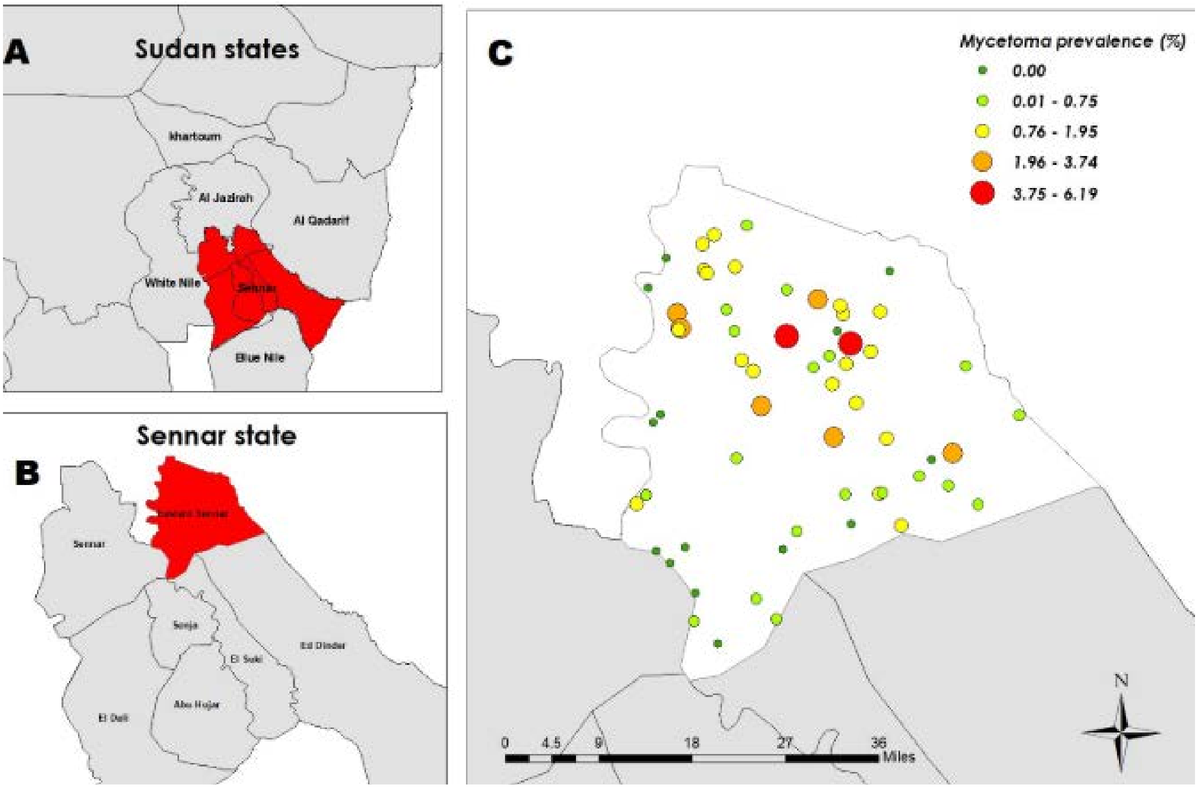

Figure 14: Map A – south-eastern states of Sudan; Map B – localities in Sennar State; Map C – geographical distribution of mycetoma by villages in Eastern Sennar locality (Hassan et al., 2021).s

Why Sennar?

According to MRC data most mycetoma patients live in the central parts of Sudan, including Al Gazira, White Nile, Khartoum, and Sennar states (Fahal et al., 2015a). This data includes a total of 6,792 individuals examined and/or treated between 1991 and 2014 (see Figure 15). Although this data does not reflect the true prevalence of the disease in the country, it was important for me to be able to choose a high-density area(s) in which to conduct fieldwork, and the data enabled me to do so.

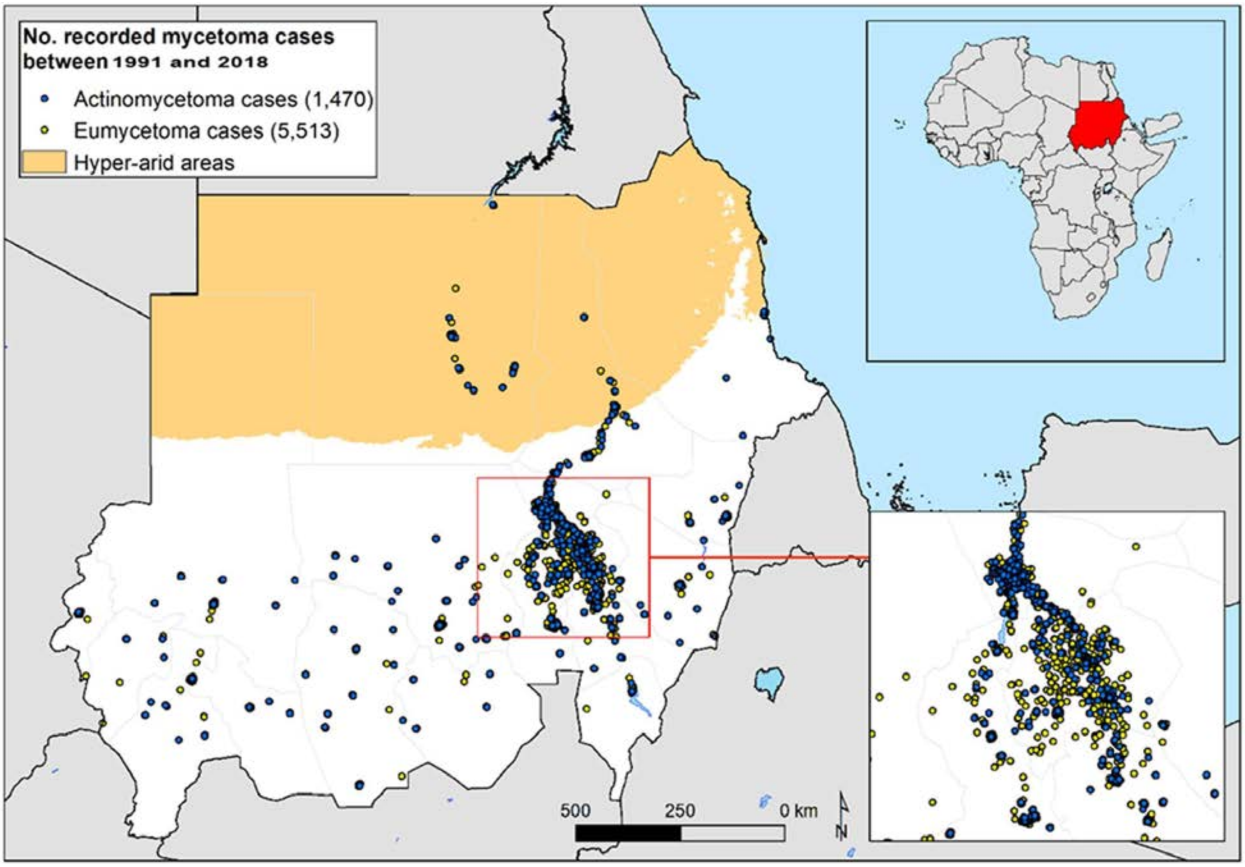

Figure 15: Mycetoma cases in Sudan (1991–2018); the blue and yellow dots represent actinomycetoma and eumycetoma, respectively.

Sennar State, central Sudan, which is located between latitudes 05.12 to 05.14 and longitudes 32.9 to 35.4, appears to have a great share of the overall mycetoma patients, certainly according to information based on the data sets collated from the MRC (Fahal et al., 2015a). Sennar State is bordered by Gazira State to the north, White Nile State to the west, Gedaref State to the east, and Blue Nile State to the south. Sudan has 18 states, and Sennar State is considered to be its heart. It has an area of 37,844 km^2, and Sinja is both the capital and the largest city of the state. The state’s population is approximately 1,402,000 inhabitants, consisting of a mix of Arabic and African ethnic groups, who depend mainly on agriculture, livestock, and crop trades for their livelihoods. The main sources of economic activity are: agriculture within the Suki irrigated scheme; the Sennar sugar factory; and employment within several fruit farms located on the riverbanks of the Blue Nile. The state also hosts the Sennar Dam, which is on the Blue Nile River, located near Sennar town. The dam was built in 1925 by the British engineer, desert explorer, and adventurer Stephen Roy Sherlock. This dam is 3,025 m long, with a maximum height of 40 m, and provides water for crop irrigation of the Al Gazira region. The areas using this water supply include farming land (traditional, mechanised, and irrigated agriculture), urban and village settlements, forests, horticulture, and grazing.

The study area was Wad Elnimear village, one of the settlements within the Wad Al Abassi area, found within Eastern Sennar locality, which consists of five areas, namely: Doka, Wad Taktok, Wad Al Abassi, Hamadna Allah, Sennar Junction, and Sugar (Ganawa et al., 2021). This is also where an epidemiological study by Ganawa and colleagues was carried out; their study showed a high cluster and density analysis for mycetoma cases within the spatial geographical distribution of Eastern Sennar locality, and especially in two areas, with Wad Al Abassi being one of them (Ganawa et al., 2021) (see Figure 16).

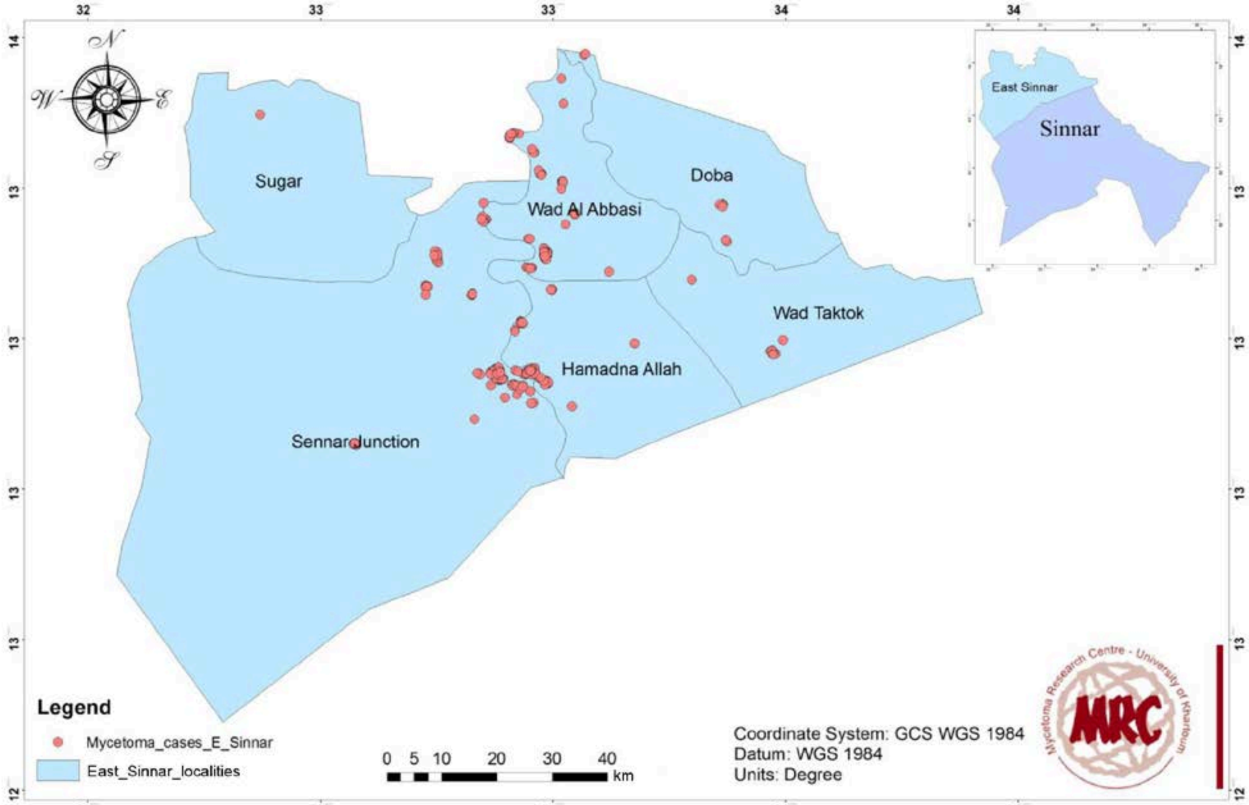

Figure 16: Mycetoma cases in Eastern Sennar locality, Sennar State, Sudan (Ganawa et al., 2021).

Types of mycetoma causative agent

Mycetoma can be caused by a number of organisms: true fungi (eumycetoma), or bacteria, (actinomycetoma) (Elkheir et al., 2020b). Of eumycetomas reported worldwide, 90 per cent are caused by only four agents, these being: 16 Madurella mycetomatis (most common), Madurella grisea, Pseudoallescheria boydii, and Leptosphaeria senegalensis (Verma & Jha, 2019). For actinomycetoma, the most common species are Nocardia spp. (mostly in regions with higher humidity), and include: Nocardia brasiliensis, Nocardia asteroides, and Nocardia otidiscaviarum. A variety of other causative organisms are also reported under the label of eumycetoma, such as: Leptosphaeria tompkinsii, Pyrenochaeta romeroi, Pyrenochaeta mackinonii, Cladophialophora bantiana, Cladophialophora mycetomatis, Curvularia geniculata, Exophiala jeanselmei, Phialophora verrucosa, Acremonium falciforme, Acremonium kiliense, Neotestudina rosatii, Fusarium moniliforme, Fusarium solani, Aspergillus nidulans, Aspergillus flavus, Cylindrocarpon cyanescens, Trichophyton spp., Microsporum spp., and Hormonema spp. Under actinomycetoma, such causatives as Actinomadura madurae, Actinomadura pelletieri, and, also, Streptomyces somaliensis, and Actinomyces Israeli are recorded (Verma & Jha, 2019).

Several studies suggest an association between mycetoma and certain environmental factors. For example, Abdalla and colleagues extracted black pigmented fungi, resembling Madurella mycetomatis, from soil samples and thorn collections. Despite failed attempts to culture the organism, we can now present data showing that it is possible to detect, by molecular methods, M. mycetomatis within the environment of the areas in Sudan where it is endemic (Ahmed et al., 2002) (see Figure 17).

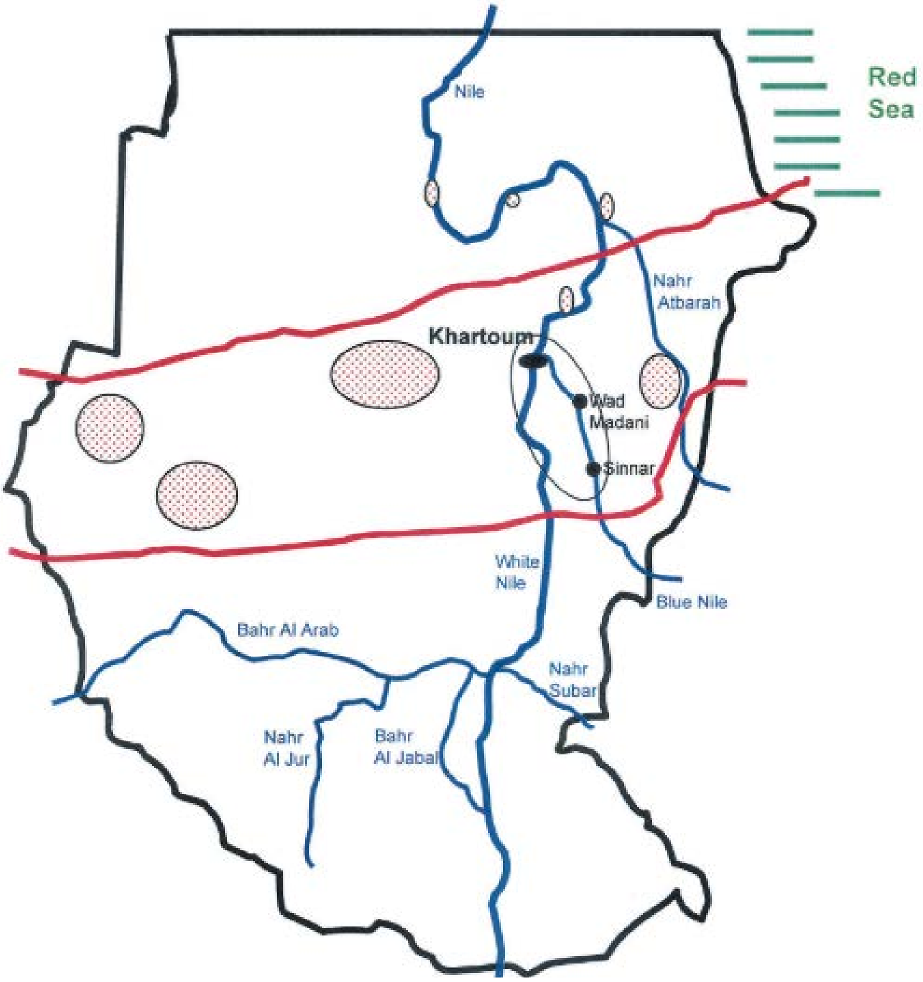

Figure 17: Sites of thorn collection and soil sampling (black spots), with mycetoma endemic areas (red dots) and mycetoma belt (red lines) (Ahmed et al., 2002).

Mycetoma cases were also seen mainly in areas with hot and dry climates, and with intermittent and short periods of heat and rainfall. The organisms causing mycetoma are found in the soil, and usually enter the human body via a thorn prick or similar trauma (Verma & Jha, 2019).

Another modelling study done by Hassen and her team predicted mycetoma occurrences in the central and south-eastern states of Sudan and along the Nile river, and indicated that dry areas proximal to water sources, soil with low concentrations of calcium and sodium, and areas with a particular variety of thorny tree species, provided the most suitable environment(s) for the occurrence of mycetoma in Sudan (Hassan et al., 2021b). The data included in this study were extracted from the patient database at the MRC. The study only included patients from Sudan who were seen at the centre during 1991–2018, and the address where they were living at the onset of symptoms was used for the analysis. These locations were remotely geo-referenced using ArcGIS 10.5 (Environmental Systems Research Institute [ESRI] Inc., Redlands CA, USA) to obtain geographical coordinates defining the mycetoma occurrence locations.

Clinical presentation

It is thought that only a few individuals report the disease, although many people may be exposed to the causative agents of mycetoma. An interplay of pathogen, host, and environment occurs in the pathogenesis of mycetoma. Inoculation of the etiologic agents occurs when a human makes contact with soil or thorns during manual activities. An interplay of pathogen, host, and environment then occurs (Emmanuel et al., 2018b).

The clinical presentation of actinomycetoma is virtually identical to that of eumycetoma, irrespective of the causative organism (Zijlstra et al., 2016). Both forms start as a painless lesion, then slowly progress when the organism reaches the subcutaneous tissue. Subcutaneous swelling and multiple secondary nodules then evolve, which may suppurate and drain through multiple sinus tracts. The sinuses usually discharge grains containing colonies of bacteria or fungi which vary in both colour and size, depending upon the organism, and are considered a unique characteristic of the disease.

If left untreated, the infection spreads to the deep structures through the fascial planes and gradually involves the underlying bone and muscle, which then renders the infection more resistant to treatment. The organism may also invade the periosteum and adjacent bones, leading to osteomyelitis. Mycetoma affecting the back may lead to vertebral compression, causing neurological manifestations. Lymphatic spread has been reported in a few cases. Other clinical variants include swelling without sinuses, a cystic type, and a verrucous plaque.

Diagnosis

Examination of grains

Caused by both fungi and filamentous bacterial agents, mycetoma grains can be indicative of the causative organism and its origin. Grains are easily visible on inspection, showing ranges of different colours, consistencies, and sizes. Grains can be collected in the form of a discharge from wound sinuses, or by fine-needle aspiration cytology. The visible features of the grains are associated with the different organisms that drive mycetoma; for example, large grains are seen with Madurella spp., A. madurae, and A. pelletieri, while the grains of N. brasiliensis and N. asteroides are smaller in size. Black grains are strongly associated with eumycetoma, which is caused by a different genus of fungi; bacterial infections may have red grains, particularly those caused by A. pelletieri. Although most grains tend to have a soft consistency, those from S. somaliensis and M. mycetomatis have tough exteriors. Different staining tests can be used to highlight specific components of the grains, for example, potassium hydroxide solutions are commonly used to show fungal hyphae.

Imaging

After diagnostic testing, imaging technologies can be used to assess the location and the extent of damage caused to bones and soft tissues. While numerous types of imaging can be used, the availability of services is commonly a bottleneck in lower-income settings. This study, therefore, considers the following imaging technologies, which may be used in high-risk zones and specialised centres:

- **Simple radiography** (including X-ray scans) can be used to assess the pathology of the disease. Findings may range from no significant deformity to vast pathologies, depending on the type of causative organism and its severity. Severe orthopaedic pathologies may include cortical thinning, hypertrophy, bone cavities, and disuse osteoporosis, with wide impacts on both the bone structures and joints affected by mycetoma. Eumycotic lesions tend to form a few cavities in the bone that are ≥10 mm in diameter, while actinomycotic cavities are often smaller, yet more numerous.
- **Ultrasonographic** characteristics can be helpful, not only in diagnosing mycetoma, but also in defining the magnitude of the injury. The ‘dog-in-circle’ sign, for example, is commonly associated with mycetoma, which portrays itself as a hyperechoic focus within hypoechoic lesions.
- **Magnetic resonance imaging (MRI)** can further complement other imaging techniques by localising the infection foci. Spherical lesions, as described by Sarris et al. (2003) can also show a low-signal matrix, which can indicate fibrous tissue, and a superimposed granuloma – presenting as high-intensity lesions with a low-signal centre – represents fungal elements and grains.

Culture

Mycetoma can also be grown in vitro through appropriate cultural mediums. Blood agar and allow organisms to grow within 7–10 days; however, this process may take as long as 6 weeks, depending on the speed of growth and suitability of the media. The organisms that cause mycetoma form a range of possible colonies, with varying morphologies, appearances, and biological activities.

Molecular diagnosis

A biopsy of a specimen from mycetoma lesions may also undergo molecular investigations, such as direct sequencing tests. Contrary to culturing techniques, this method can isolate the pathogen much faster for a rapid diagnosis. Molecular diagnosis is able to further differentiate between a bacterial agent and a fungal one, which is particularly helpful when culture results are inconclusive. The 16s RNA gene sequencing studies are among the most commonly used, although others, such as loop-mediated isothermal amplification, may be used as alternatives.

Treatment

Despite centuries of recognition, the treatment of mycetoma infections remains challenging, difficult, and disappointing. To the present day, there are no uniform treatments for the management of mycetoma, and no guidelines exist. Therefore, there remains a long road ahead of us before we can properly manage mycetoma patients and develop effective control programmes, treatment guidelines, or protocols. The existent treatment is based on personal experiences, or a few published case reports and case series (Elkheir et al., 2020b). Several studies indicate the ongoing need for greater efforts to be made for the better management of mycetoma cases (Fahal et al., 2015b).

There is a wider range of treatment options available for actinomycetoma than for eumycetoma (Verma & Jha, 2019), and the latter is more difficult to treat. The treatment for each case is totally dependent on its etiological agent and the extent of the disease (Fahal, 2010). Until recent years, the only available treatment for mycetoma was amputation of the affected part, or multiple mutilating surgical excisions (Fahal, 2010). No case of self-cure has ever been reported in the medical literature, according to the director of the MRC. However, spontaneous lesion regression has been observed in some patients (Fahal, 2010).

Generally, the azoles family remain the most commonly used class of antifungal drugs in the treatment of eumycetoma. Ketoconazole was used formerly, before it was then banned in 2013, due to its life-threatening hepatotoxicity (see Elkheir et al., 2020b; Fahal et al., 2011). Currently, the treatment starts with a preoperative antifungal treatment for six months, which then continues postoperatively for at least a further six months (Elkheir et al., 2020b). Treatments for eumycetoma include: ketoconazole (400 mg/day), itraconazole (200–

400 mg/day), posaconazole (200 mg, four times daily), voriconazole (400–600 mg/day), amphotericin B (0.5–1.25 mg/kg per day), and terbinafine (500–1000 mg/day). These treatments can be administered either alone, or in any combination. The time taken for remission in actinomycetoma can vary from three months to one year, whereas eumycetoma requires prolonged treatment ranging from one to three years. There are reported cases where the treatment duration has reached 40 years (Hassan et al., 2021a).

Adverse effects of treatment

The available drugs for the treatment of eumycetoma need a long period in which to effect a cure. The recurrence rate after the cessation of treatment with these drugs is high. The drugs are expensive, and their prolonged use has proved not to be cost effective for the health authorities and patients (Fahal et al., 2011).

A notable adverse effect of these drugs is reported hepatotoxicity, hence every patient is required to provide a liver function test every six weeks during their follow-up visits, and to remain aware of the possibility for gynecomastia, lip dryness and ulceration, skin hyperpigmentation, and decreased libido. Itraconazole is contraindicated in patients with evidence of ventricular dysfunction, such as congestive heart failure, or with a history of congestive heart failure (Welsh et al., 2014).

Surgical treatment

On a case-by-case basis, surgical intervention against mycetoma may sometimes be indicated. In some situations, the objective may be to reduce the organisms’ load where the lesions are very large, while in others, it may be to completely excise a small lesion. In Sudan, only a limited number of health facilities have the capacity to conduct surgical mitigation or treatment.

The MRC is the largest specialised centre and although it is based in the capital city, Khartoum, the centre actively sends out mobile health missions to expand the reach of both surgical and medical treatments for mycetoma. For example, from 2013 to 2020, more than 15 medical missions were arranged to the Eastern Sennar State – which is a rural region of focus throughout this thesis – in order to mitigate the barriers of access in the region. Numerous patients who were diagnosed with localised mycetoma underwent wide local surgical excisions under spinal or ketamine analgesia, also combined with 400 mg oral itraconazole, while those with more advanced mycetoma were referred to the MRC for further assessment, investigations, and management (Mohamed et al., 2021).

The social aspects of mycetoma

Mycetoma is a neglected, debilitating disease, with lifelong physical and psychological sequelae affecting young and poor individuals, which adds significant social and economic burden in the country of Sudan. Some aspects of the community prevention programmes do not yield their potential maximum benefits due to a lack of sociocultural understanding of the local society, which illustrates the role of community behaviour in the success of prevention programmes.

Like any other NTD, mycetoma is considered a social stigma (Van de Sande et al., 2017b). Although mycetoma affects mainly males, the stigma is more common among females and children (Bakhiet et al., 2018a). This stigma can then lead to social, psychological, and further health consequences.

Mycetoma is a disease afflicting people of low socio-economic status; most of the individuals directly affected by the disease live in remote areas, and away from the only centre that provides specialised care for mycetoma (Abbas et al., 2018; Nenoff et al., 2015). Most patients present late, with advanced disease status and serious complications. Bakhiet et al. (2018a) claim this to be the consequence of the painless nature of the disease, patients’ low health-education level, and the lack of health facilities in endemic areas. According to the distribution of the disease in Sudan, where mycetoma is a disease of remotely located people, the most affected states are: Gazira State (providing 37 per cent of the MRC patients), White Nile State (12 per cent), followed by 11 per cent recorded from North Kordofan State, along with Sennar, Gedaref, and Kassala states (Fahal et al., 2015). All these areas are far from Khartoum, where the MRC is located; the MRC is the primary service provider for mycetoma patients, hence most of the affected population need to travel for long distances to reach the centre for the free drugs and follow-ups every six weeks.

Most of the individuals affected with mycetoma seek medical advice in the late stages of the disease, and the time taken between the initial signs and symptoms to obtaining medical care ranges from 2 to 420 months (mean 77.6 months) (Fahal et al., 2015; Sampaio et al., 2017). Their presenting late increases the possibility of surgical intervention, which then leads to a higher possibility of recurrence and disability. Besides which, the high costs of the diagnostic tests and treatment total around US$2,500 per year, whereas the annual income in Sudan is less than US$400 per capita (according to the UNDP, 2006). These costs add a still greater burden onto the patients, their families, communities, and, eventually, onto the entire health system in Sudan (Bakhiet et al., 2018a).

Although mycetoma affects all age groups (Bakhiet et al., 2018a), most of the individuals who encounter the disease are from younger age groups, and 64 per cent of mycetoma patients who present to the MRC are less than 30 years old (Fahal et al., 2015). This may add increased burden on families, since these are the active age groups capable of supporting the other members of the family. These afflicted young individuals may subsequently encounter difficulty in finding a job and getting married.

A further factor is the chronicity of the disease and the long duration of the treatment. Mycetoma is a chronic disease, the mean duration of which is three years, and more than 13 per cent of patients have mycetoma for more than 10 years, with one reported case of 60 years (Fahal et al., 2015). In addition, there is a low cure rate of 25.9 per cent, especially with eumycetoma, while the susceptibility to complications such as amputation is 2.8 per cent (Fahal, 2017a).

Mycetoma constitutes a diagnostic and management dilemma: it remains challenging and difficult to treat mycetoma patients. The current treatment is disappointing, with a low cure rate (Zein et al., 2012). For a better outcome from the disease, both surgery and prolonged antifungal treatments are necessary, which lead to a higher rate of recurrence (see Bakhiet et al., 2018b; Fahal, 2017b; Zein et al., 2012).

Due to the painless lesions, the silent onset of the disease, and the fact that affected individuals tend to live in remote areas, in addition to the low socio-economic status of those affected, most of those who seek treatment do so only in the late stages of the disease (Edwar Siddig, 2017; Sampaio et al., 2017). Hence, the disease tends to become more progressive, and subsequently necessitates surgical involvements that lead to lifelong disabilities, which in turn place greater burden and stigma both on the individuals who are diagnosed with the disease and on their families (Edwar Siddig, 2017; Sampaio et al., 2017). The associated stigma has severe socio-economic consequences, including a higher rate of drop-out from school for infected children as compared with non-mycetoma patients. Mycetoma can also negatively affect the marital status and employment of young adults. Moreover, individuals who are diagnosed with the disease are affected psychologically because of the lack of health services, physical disability, and a lack of future prospects, particularly as the outcome of treatment is weak and often leads to amputation of the affected part (Fahal, 2004b; Sampaio et al., 2017).

In terms of mycetoma, Sudan is the most significantly affected part of the globe, yet the prevalence of the disease is unknown and its management is not uniform (Sampaio et al., 2017; Van de Sande et al., 2017b; Zijlstra et al., 2016). There are no preventive or control programmes, and no early-case recognition or surveillance systems (Hay & Fahal, 2014). Moreover, the knowledge regarding the sociocultural understanding of the disease remains limited to case reports and to passive case detection (Bakhiet et al., 2018a). There is no study of mycetoma addressing the sociocultural aspects of the disease in a detailed qualitative way.

To my knowledge, this study is the first of its type in Sudan to explore the disease and its social and cultural aspects from an anthropological perspective, and to then assess how individuals affected by mycetoma experience the illness, alongside their families, their community, and healthcare providers, as well as the vital service providers, all using the lens of medical anthropology. The study may provide a better understanding of the community perspective, and also assist in identifying the gaps between all of these layers, so as to suggest a preventive strategy for mycetoma that involves all stakeholders, and takes into account the needs and behaviours of afflicted communities and individuals within their context and culture.

This chapter concludes that NTDs have a significant burden in tropical areas, that they are slowly taking a space in the global health arena, and that, just as with all other diseases, it is crucially important that their social and other determinants of health be studied. Mycetoma was recently added to the list of NTDs by the WHO, Sudan has the highest burden of the disease, and no epidemiological or social studies have been carried out in Sennar and Wad Elnimear village.

This chapter has also highlighted the power of international institutions such as the WHO, which lies in their ability to bring nations and stakeholders together in a collective effort to address global health challenges. Through promoting knowledge sharing, resource pooling, and joint initiatives, such institutions can amplify the impact of individual efforts, resulting in significant power. Similar international institutions, and through its diverse network of experts, researchers, and health professionals who contribute to evidence-based decision-making. These organisations engage in rigorous research, collaborate with renowned institutions such as the MRC, and produce credible health data and analyses. The WHO’s power extends to its influence in shaping global health priorities and coordinating efforts to address pressing health issues (Gostin & Katz, 2016).

Chapter Four

The Artificial Animal Enclosure Project

Chapter Four: The Artificial Animal Enclosure Project

Introduction

Walking around Wad Elnimear village in East Sennar, we observed two separate and distinct groups of houses. Most homes were clearly built using mud and soil; some were clustered and others more distantly located. Near every house there were animal enclosures with cows and goats contained inside. The village was dusty, hot, and dry as it usually is in April. In some areas we saw evidence that the villagers had previously torn down steel animal enclosures, and replaced them with natural fencing made with tree branches. Knowing that the steel enclosures had been built by a national firm for mycetoma prevention, we wanted to understand why the villagers had removed them. The more questions we asked, the clearer it became that the issue was centred around mycetoma. Livestock herding is a big part of the village's norms. They have been herding both domesticated and wild cattle and enclosing them with thorny branches and bushes for decades. Generations of villagers across the region have learned to build thorn enclosures. Later, it became known that a collaboration between the Sennar State Ministry of Health (SMOH), the Mycetoma Research Centre (MRC), and a Sudanese engineering company named SINMAR had built the steel animal enclosures as a replacement for the thorn enclosures that have been used by regional livestock herders for generations. However, the highly expensive steel facility was ultimately futile as hardly any of the villagers used it. Thorn enclosures caused routine scrapes and cuts, which may initially appear harmless, but are thought to be conduits for aerobic actinomycetes bacteria and certain fungal species (organisms responsible for the transmission of mycetoma) to enter the body (Ahmed et al., 2002). This chapter explains why these artificial animal enclosures were not used, with reference to the perspectives of both the local community members and government officials.

Animal herding in Wad Elnimear

Wad Elnimear is an African Sudanese village with high local and national rates of mycetoma. It is located in the eastern part of Sennar State, which is prone to annual flooding between spells of heat. A 2010 United Nations Development Programme (UNDP) assessment on employment opportunities revealed that most job prospects were across the agriculture and livestock industries, or in small businesses and partnership working groups. The primary source of livelihood for people locally is agriculture, with sugar and fruit being the main income-generating crops. Animal herding is also a common income-generating activity, with the most frequently used types of animals being cows, goats, and sheep. In the study village, animals constituted a significant source of income and also indicated one’s status in the village (both socio-economic status and subsequent personal/familial power). Cows were the preferred animal to herd but are now considered expensive to graze due to growing economic deprivations. Consequently, goats are now preferred due to their lower overhead costs and high financial returns. Livestock are considered essential for their meat and milk and they can be easily converted to cash when people are in need. This is a matter of longstanding, highly valued, and honoured sociocultural tradition, as well as of subsistence. It is a common custom in this region to feed visitors, and serving one’s livestock to guests fulfils specific social commitments that are held in high regard in the village. Livestock is also central to most celebrations and festivities, especially as it is considered a signal of good social, societal, and cultural standing; furthermore, it communicates hospitality and a good ‘hosting’ culture to buy/use the meat and milk of fresh livestock to present to new hosts, loved ones, and relatives in large gatherings and celebrations.

The metal animal enclosures

In Wad Elnimear village, branches from the thorny threes are used as the primary material with which to build fences around people’s homes (see Figures 18). These thorny fences not only define private property boundaries, but also serve as animal enclosures for household livestock. They provide a sense of security that animals will not escape during the night and also protect the animals from wild predators that come in from the surrounding areas. Fences made of thorny branches are also erected around trees to prevent animals from eating the leaves and destroying the natural shrubs and environment around the enclosures.

In order to prevent mycetoma in Sudan, between 2010 and 2013 an integrated patient management model, structured at village level, was set up and successfully launched (Fahal et al., 2014). However, the intervention outlined here was launched more recently, taking place in 2018, and was a collaboration between the SMOH, a non-governmental NTD research group, and a development organisation, financed by a national private company. This company provided materials for the alternative fencing structures, overseeing the construction of 72 steel animal enclosures (see Figure 19). This intervention was designed to help prevent scratches from the thorn animal enclosures through the use of a safer material. These enclosures did not surround the family compounds, instead being located about a mile away from the cluster of village housing. The enclosures were communal, so that each neighbour’s livestock lived in adjoining squares of equal size, with one side of each square being shared. The enclosures consisted of three steel bars, which were set at ankle/shin height, thigh/waist height, and chest height, supposedly to prevent livestock from escaping (see Figure 19). All the enclosures were built and offered free of charge to the villagers (Bakhiet et al., 2018).

Figure 18: Father and son using the thorny trees to build a traditional animal enclosure.

Figure 19: Empty artificial animal closure, illustrating the positioning of the steel bars.

Figure 20: One of the remaining three, distant, steel animal enclosures, completely surrounded by thorny branches.

There were public meetings in Wad Elnimear village, in which implementing officials from across the collaboration presented their plans to erect these metal enclosures to the villagers and explained the benefits of using them. There was an in-built component of community engagement. However, most community members resisted moving their livestock from their home compounds to the distant steel enclosures; they preferred using the thorny materials and living side-by-side with their animals. The government issued directives and the police gave warnings for people to comply with the movement of their livestock to the ‘better’, safer option of the steel structures. Despite pressure from the government and police, during my visit in 2018 only three of the seventy-two enclosures were being used. It is important to consider alongside this the growing distrust of villagers towards the government nationally during this time. The three steel enclosures that were actively being used for village livestock had additional thorn fencing surrounding them (see Figure 20), indicating a preference for thorn fencing. When I asked a national government official why the steel enclosures were not being used, and why the few enclosures that were in use had thorny branch modifications, he responded: “because people here are ignorant”.

In this analysis, I attempt to better understand the perspectives and experiences of the different stakeholders: the staff working at the MRC, the state government officials, and the people of Wad Elnimear village. I also consider the demands and pragmatic issues of such a ‘resolution’ and its subsequent local rejection. Further, I explore the power dynamics across the different actors in this intervention as a global health intervention, and I reflect on how power imbalances affected the success/failure of this intervention.

Results

In this section, I present the results of the thematic analysis, along with my observations on the perspectives of the various actors involved in the animal enclosure project. I delve into whether they perceived the project as a failure or as a success and explore the underlying reasons for their viewpoints.

The perspectives of government officials

According to government officials there were two main reasons for the ultimate failure of the steel animal enclosures: ignorance and poor enforcement.

Government officials expressed general frustration about the fact that community members did not use the steel enclosures, and that even in the rare times when they did use them, thorny branches were added too, rendering the whole operation towards mycetoma prevention obsolete. These officials suggested that the reason the enclosures were not used was simply down to the ignorance of the community, rather than because of their specific, conscious ‘viewpoints’ or as acts of choice or resistance:

> Respondent 1: It is just ignorance, as I already told you: they are ignorant, and this is their character.
>
> Researcher: How can we solve this issue [i.e. of the community’s not using the new enclosures]?
>
> Respondent 1: This is how they are, we need to be patient.
>
> Respondent 2: But I don’t think this can be solved. I swear they will never change; I know them very well.

(Focus group discussion with government officials)

The government officials thought that illiteracy among the community members implied a certain level of ignorance that rendered them unable to appreciate the value of the steel enclosures, despite the government’s considering the new enclosures as a favour to the local community. Many government officials used derogatory names for community members, calling them ‘thieves’, and accused them of stealing the steel and re-selling it. They expressed that the community of this village were historically migrants, of various racial descents and from distant lands, and that they had criminal records and were ‘known’ to be thieves:

> Government Official: They are migrants and are very greedy. They will always ask for more without helping themselves ... We have lived with them for a long period of time, we know their behaviour, everyone [in this village] wants one enclosure for himself – they want everything to be ready for them… bed, electricity, and tank with water supply.

The villagers were perceived by most government officials as having multiple negative characteristics, such as greed, ignorance, and laziness, with undertones that speak to their racial background, low education levels, and history of migration. Although one government official did acknowledge that many community members may have felt anxious about moving their livestock from their home compounds to distant enclosures, other officials disagreed with him:

> Respondent 1: As I understand from them [the community members], they don’t want to put their animals inside the artificial animal enclosures because they fear, they want to protect their animals.
>
> Researcher: Protect [them] from what?
>
> Respondent 1: From being stolen.
>
> All participants of the group then started to speak together:
>
> Respondent 2 [joined by others]: ... but they themselves are thieves. They don’t want to leave their animals outside, it’s their nature, they grew up like this.
>
> (Focus group discussion with government officials)

All of the interviewed government officials agreed that the intervention failed because state authorities could not properly enforce the use of the enclosures. There is differential power between state and federal governments nationally, and state-level governments do not always have the legislative power to enforce a federal government directive. This was felt to be the case regarding the steel animal enclosures, with the representative government officials in this study perceiving state authority as ineffective: “I think the executive power in the state was weak, they were indolent” (Government Official).

The community were given notice by the federal government to evacuate the traditional animal enclosures, but most people did not do this. State government officials said that despite the fact that villagers were not following national governmental directives, they could not do anything about it, as the forms of executive power necessary for such action could only be afforded directly by federal government to local or state government. Some villagers did not respond to the directives; state-level officials were unable to do anything in response, and they subsequently expressed considerable dismay and frustration with both the federal government and community members in their explanations. It was clear that they felt under-supported by the federal government, and unheard by the community. Their frustration was often positioned as being a practical issue, indicating a need for more efficient state-level resources: “more police surveillance was needed to make the people use the enclosures” (Government Official).

Indeed, this was identified by government officials as being a matter of hierarchy, authority, and their ability (or lack of it) to take ‘official’ action to back up legislative decisions. Some officials also thought that there was a lack of proper follow-up and maintenance for the intervention from the state administration, which also resulted in the perceived failure of the project. An inability to communicate across different levels of social and political authority was frequently returned to as a fundamental element of the failure of this (and potentially other) interventions.

The perspectives of community members

The villagers, on the other hand, provided a variety of different reasons as to why they did not use the new enclosures, which often contrasted with the perspectives of the government officials.

The relationship that people have with their livestock is of paramount importance to their way of life and experience of wellbeing. This relationship is predicated on a sense of personal ownership of the animals and signified fiscal stability. This personal individual ownership was seen as being directly threatened by the steel enclosures, as they subsumed personal possession and individual rights into a space that created ‘community ownership’. The perception that the animals were becoming ‘community’ property through the practical use of the new structures also caused a level of confusion, which was interpreted as inhibiting the proper care of livestock: “When I put the cows into my own cage, I can observe them carefully, but when I put them in their one, I get confused” (Villager).

Interaction with one’s animals is an integral part of everyday life. Community members described a strong need to keep their animals as close as possible so that they could both see and hear them, and regularly interact with them. As was explicitly stated: “I feel content when I hear the noise of the animals beside my house, I even can hear them when I am asleep” (Villager).

It was interesting to note that two villagers who used the new enclosures were nervous to leave the animals alone at night. They placed their beds near the steel enclosures, sleeping there instead of at home (see Figure 21).

Figure 21: This picture is taken after one of the FGDs, at night, in front of one of the artificial animal enclosures; it shows two beds for sleeping on, for those who prefer to keep their animals in the artificial animal enclosures.

Many practical issues were raised by community members as being principal reasons for non-use of the steel enclosures. The animal enclosures were too distant from their houses and it took such a long time to reach the new enclosures that it was considered to be too much trouble to access them and impossible as an everyday activity. Almost all community members that were interviewed explained that they preferred to keep their cows close to them during their morning custom: a dawn routine including cleaning their cows and treating them each day before then walking to their farms, which tended to be far away from the village. In the evening, after returning from their daily agricultural work, people would then milk their cows for dinner. If the cows were kept far from the villagers' homes, people would be unable either to adequately care for their cows, or to consume the cows' milk after a laborious day of work. Simply put, the new enclosures were too far from people's day-to-day activities and the new location was inconvenient.

Unlike the newly installed steel animal enclosures, the thorn enclosures serve multiple functions. Cows are required to have regular prepared feeding throughout the year, except during the early rainy seasons (June–August), when they can be grazed outside in the fields. This is linked to seasonal changes and shifts in herding across the region. Hence, many villagers indicated that the thorny animal enclosures served as effective locations for the storage of this food. In this context, the thorny branches that are used around the enclosures have a function that was not considered in the implementation of the artificial enclosures – that of preventing the animals from reaching the food the villagers have stored for them (rather than protecting the animals *as* food) – which is the opposite function to that of the steel enclosures. Given this common usage, in many cases the thorn enclosures are utilised for the storage of dry human food (such as grains and seeds), as well as for any foods that need exposure to the sun for an extended period of time (e.g., onions and dried ingredients). Considering the warm and dry climate, this practice protected the community against various food-borne illnesses through natural means.

Design issues with the steel enclosures

Design and implementation-level issues were equally important, as the practicality and aesthetic of the enclosures was valued by the villagers. All community respondents stated that they thought there were significant problems in the design of the new animal enclosures, and that these enclosures were technically inefficient. The new animal enclosures were built from a relatively weak steel that could not resist the power of the bigger cows and larger animals. Doors were particular areas of structural vulnerability, and were considered as the weakest points in the enclosures by village members: “Some cows actually hit and managed to break the enclosure” (Villager).

Furthermore, because of the relatively wide distances between the steel bars, the new animal enclosures were unsuitable for housing goats and young cows and calves that could get through the spaces. This was difficult, as some villagers only had goats: “How can I keep my goats in such a cage where it can easily escape?” (Villager).

Additionally, young cows sometimes need to be isolated from their mothers in order to facilitate milk build-up and production. The new enclosures could not serve this function due to their structural design. Further, people often preferred to walk through the enclosures to reach a specific enclosure/space, but the current design did not allow for people to conveniently pass through them, and urged people to walk around them instead.

To overcome these perceived practical/structural faults, some villagers made secondary thorn enclosures *inside* the steel enclosures, resulting in a hybrid structure for their animals (see Figure 22), thereby undermining the intervention and the project's objectives.

Figure 22: Another steel enclosure still in use, demonstrating a hybrid thorny branch and steel structure.

In terms of aesthetics, the thorn enclosures are circular in shape and therefore very dissimilar to the steel enclosures, which are designed and built as squares. This geometric shape is unfamiliar, resulting in enclosures that were significantly different to those that community members have been accustomed to for generations. This aesthetic factor further increased reluctance to usage.

The villagers claimed that when government officials introduced the idea of steel enclosures, the villagers were told that there would be small rooms inside the enclosures for calves and their food. They were also told that there would be water tanks around the enclosures and trees planted inside the enclosures. However, none of these promises materialised, with a far more 'basic' steel structure being produced despite what was communicated originally. This generated a sense of distrust among the villagers regarding the joint government and private business project: "Where are those tanks? The trees that the government officials promised? They must have stolen the money from the budget allocated to the project" (Villager).

Some villagers also complained about the allocation of enclosures, which they thought had been both unequitable and unfair; demonstrating an ethical issue with the implementation of the project. Some villagers who had animals did not get enclosures, whereas others were given an enclosure without having animals: “They give to those who they already want to give to, and they ban those who they already want to ban” (Villager).

The perspectives of staff working at the MRC

During my time at the MRC, prior to conducting ethnographic research and field visits to Wad Elnimear village, I was consistently exposed to the centre’s view that the animal enclosure project described above was a highly successful intervention. This project was presented to me as a well-coordinated effort that effectively allocated resources and fostered collaboration among various stakeholders. The centre’s reputation was strengthened by the visits of numerous delegations from diplomatic and scientific bodies, who were all introduced to the animal enclosure model as an exemplary representation of the centre’s holistic approach to addressing mycetoma disease in Sudan. These achievements were proudly highlighted as evidence of the centre’s ability to actively engage the community. In fact, the MRC published an article presenting the animal enclosure project as a successful intervention for mycetoma (Bakhiet, 2018).

Throughout my time at the MRC, I unquestioningly accepted this narrative about the project’s success. As a research assistant, I actively showcased the animal enclosure model to various visitors, presenting it as an accomplishment led by the centre. However, it was not until I had the opportunity to visit the animal enclosure project for the first time, accompanied by my supervisor and the MRC team in Wad Elnimear, that I started to recognise the potential biases clouding my perspective. The reality of the situation became more apparent during that visit, yet even then, the leader of the MRC continued to assert the artificial animal enclosure project as a resounding achievement.

In the aftermath of my field visits, the staff at the MRC persisted in characterising the project as a success from their side as they had succeeded in building the enclosures; in addition, they blamed the people in Wad Elnimear for the lack of sustainability, insinuating that they lacked awareness of their own best interests. This shift in narrative raised important questions from a critical medical anthropology perspective. It prompted me to examine the power dynamics at play and the underlying assumptions about knowledge, agency, and cultural competence that shape the interventions implemented by medical institutions. Furthermore, it highlighted the need to critically evaluate the ways in which success and failure are constructed, particularly in relation to marginalised communities and their own perceptions of wellbeing and development.

Discussion

The animal enclosure problematic demonstrates a classic case of a hierarchical approach towards public health intervention, in which: “Vertical top-down programmes pass information ‘down’ but not ‘up’” (Feierman et al., 2010). The SMOH, a non-governmental NTD research organisation, and a private national corporation collaborated to design and construct steel animal enclosures in a mycetoma-endemic village; the project was clearly intended to respond to a gap in public health programming, and to contextualise the programme to rural villages. The purpose of these steel enclosures was to prevent scratches from the thorn animal enclosures, as this is a major cause of mycetoma, especially among herders and animal owners. However, the project did not succeed as hardly anyone among the local community used the enclosures. This study explored the roles of the divergent perceptions of the government officials and the villagers on the enactment of the animal enclosure project.

We revealed that government officials and villagers have completely contrasting views on the failure and original necessity of the project, indicating a lack of communication channels from planning to implementation to evaluation. While government officials think that the ignorance of the villagers and the lack of official enforcement to induce complicity with government directives to use the steel enclosures are the main reasons for the failure of the project, the villagers identified several other structural, social, and cultural barriers – most of which were either unknown to the government officials or dismissed as primitive. This was partly a matter of conflicting value systems, as well as of divergent interpretive and explanatory forms.

The government officials framed the problem structurally as a governmental and legislative issue, also referencing the perceived historical and personal ‘inferiority’ of the villagers, whereas, understandably, the villagers framed it as an issue of fundamental incompatibility with their lifeworld. There was a sense of issuing commands rather than engaging in dialogue, and when those commands were disregarded by the villagers, the solution was thought to be more enforcement and penalisation – a measure the state government was underpowered to enact, resulting in a build-up of frustrations.

It is important to note that no intervention takes place in a social and political vacuum. This particular approach worked against local circumstances by ignoring the details of the regional political, historical, and social contexts. In doing so, this intervention also impeded successful communication between different layers of the current social hierarchy, with individuals dismissing others who were identified with ‘lower’ or ‘higher’ social groups or roles. This also introduced competing values, alongside *mutual* distrust between the government officials and community members. Unless ensured through enforceable legal measures, the success of such top-down, or vertical, interventions depends on the *voluntary* cooperation and support of local populations. This study clearly shows that the local voices of the villagers were not being heard, or listened to, either before, during, or after the establishment of the artificial enclosures; effectively illustrating how such a seemingly scientific approach may go dramatically wrong.

This failure of mutual communication resulted in multiple, and often contradictory, reactions and effects. To a certain extent, the issue was a matter of representational misunderstanding and of unsuccessful inter-relational interactions. In particular, there was an inability among those planning the intervention to recognise or even acknowledge local concerns or anxieties, just as there was little local-community appreciation for the types of anxieties expressed by government officials. Of particular importance was the lack of trust within and between the different social groups. Government officials made frequent references to “how they [the villagers] are” (Government Official; above), implying an endemic hierarchy based upon the ‘natural’ or ‘poor’ character and low individual status of the villagers; the villagers, equally, referred to being actively “let down” by both the government and the private company funding and planning the project. As can be clearly seen in our findings, much of this miscommunication was introduced through a contradiction in perspectival and interpretive positions and experiences. However, this was rendered even more complex by the fact that these oppositional perspectives were often expressed in the same language, form, or narrative representation. For example, the government officials openly referred to the village communities as being “thieves”; yet the village members also stated that the officials must have “stolen the money” (i.e., “they were themselves thieves”; above), which then resulted in the inadequate final intervention, from the perspective of the villagers. Even so, despite their shared language, they regularly misunderstood and misrepresented one another – the word ‘thieves’ meant something very different for the separate social groups, and local ethics were seen as being distinct from *structural* ethics (i.e., national-level political and legal policy-ethics; and/or sociocultural ethical systems at a country-wide scale (Candea et al., 2015;

Laidlaw et al., 2018)). Ingold (2013) refers to such structural ethics as being “essentialising”, and other studies have analysed how focusing only on structural ethics emphasises top-down conceptualisations of indigenous knowledge that presuppose a uniform concept (Zanotti & Palomino-Schalscha, 2015). The misrepresentations were shown as being possible through generalisation and hierarchical top-down interventional planning by these researchers; these findings were also demonstrated in the ethnographic observations made during this field research.

The lack of trust between villagers and government officials both fostered by and resulting from miscommunication was also largely attributable to an absence of respect between these groups. This is clear when considering the primacy of human–animal relations as a source of socio-economic stability, community status, and personal–familial ‘identities’ among villagers. However, these same ‘identities’ were often dismissed by government officials as being ‘dirty’, ‘ignorant’, or ‘low’. This resulted in villagers feeling dismissed as people and as a community by government representatives, even while the officials were ostensibly planning interventions to ‘help on the ground’. Officials may have been planning help, yet it was perceived by the villagers that such ‘help’ did not accurately recognise their need, nor did it respect their norms or respond to their concerns. Even when their needs were recognised (e.g., a demand for mycetoma prevention), it was not *authentically* recognised, in terms of which type of help would be understood by the local community themselves as *helpful.* As such, questions regarding intervention must be considered as being both practical *and* moral simultaneously, in other words, ontologically resonant on multiple levels.

This is a familiar argument within ongoing health promotion, representations of indigenous knowledge, and other ‘peripheral’ development debates, many of which articulate that the difference between providing intervention ‘with’ communities and ‘for’ communities is one of fundamentally opposite approaches. Over the past three decades, researchers have considered the significance of community perspectives and how these can be engaged, involved, and authentically represented. Too many to list here, these have taken multiple theoretical standpoints ranging from the structural, to the phenomenological, and to the exclusively political and economic, among many others (e.g., Benessia, 2012; Lather, 1986; Spangenberg 2011; Zanotti & Palomino-Schalscha, 2015). Seen through a wider development and aid lens, these statements are not dissimilar to that which was articulated in the shared ‘open letter’ presented to the WHO by a large collective of “autochthonous peoples and medical anthropologists”, calling for a “new definition of health” that would recognise multiplicities of perceptions of what ‘health’ may be or include (see Charlier et al., 2017). This has also been represented as a form of research ‘praxis’, which “accommodates hybridised approaches and other ways of knowing”; this is necessitated by “plural co-existence” (Zanotti & Palomino-Schalscha, 2015).

The artificial animal enclosure project is an example of a global health intervention that did not achieve its maximum expected outcome. In global health initiatives, it is important to recognise that challenges can arise not only from the cultural beliefs of local communities but also from the cultural beliefs and biases of the intervening organisations themselves. For instance, a fixation on local ignorance and a neglect of local livelihoods and food systems can hinder the effectiveness of interventions.

Randall Packard’s book *A History of Global Health: Interventions into the Lives of Other Peoples* (Packard, 2016) sheds light on the various interventions made by global health initiatives into the lives of people in different parts of the world. The book offers a comprehensive analysis of the historical development and impact of global health interventions, highlighting the complexities and challenges associated with such endeavours.

Packard’s book focuses on how global health initiatives have sought to address health issues in diverse communities worldwide. The subtitle highlights the inherent power dynamics and ethical considerations involved in these interventions, acknowledging the often-asymmetrical relationships between the global health community and the communities being targeted. One such example is the smallpox eradication campaigns. Despite eventually succeeding in eradicating smallpox, these campaigns initially faced resistance from communities due to cultural beliefs and suspicion of foreign intervention (Packard, 2016). Logistical difficulties and limited community engagement further hindered the success of these campaigns.

Malaria control programmes have also encountered obstacles. The focus on indoor residual spraying with insecticides such as DDT encountered resistance in certain communities. Insecticide resistance, weak infrastructure, and socio-economic disparities contributed to the failure of these interventions. A neglect of broader health systems and socio-economic determinants limited the impact of such initiatives in effectively controlling malaria.

Early HIV/AIDS prevention efforts also neglected crucial cultural, social, and economic factors, leading to limited success in curbing the epidemic. Interventions primarily focused on individual behaviour change and promoting condom use, overlooking social dynamics, gender inequalities, and stigma. The failure to address these complex factors undermined the effectiveness of prevention efforts in certain communities and regions.

The implementation of structural adjustment programmes had unintended consequences on health systems in low-income countries. Budget cuts in public health resulted in reduced access to essential services and weakened healthcare infrastructure. These programmes, aimed at economic stabilisation, failed to consider the impact on public health, leading to a decreased availability of medication and trained healthcare workers.

Perhaps more relevant examples of global health interventions, in the case of NTDs in Sudan, are those pertaining to Guinea worm disease and river blindness, which remain persistent in certain regions in the southern parts of Sudan and South Sudan, mostly due to limited attention, funding, and lack of political will (Packard, 2016). The effective management of these diseases requires comprehensive approaches that address vector control, cultural beliefs, and socio-economic factors. However, an inadequate understanding of the complexity of these diseases and insufficient resources have contributed to the failure in their effective control and elimination (Packard, 2016).

All these examples underscore the importance of considering cultural beliefs, engaging communities, addressing social determinants of health, and ensuring comprehensive approaches in global health interventions. Failure to address these factors, along with logistical difficulties, resistance from communities, and limited resources, has led to the failure of these initiatives in achieving their intended outcomes.

In 1986 Merrill Singer emphasised the importance of understanding the broader social, economic, and political contexts in which health issues arise. Singer argued that health problems cannot be separated from the social structures and power dynamics that shape them (Singer, 1986). This perspective resonates with the analysis of global health interventions as well as the artificial animal enclosure project, as it highlights the influence of cultural beliefs, social determinants, and power differentials on the outcomes of these interventions.

Critical medical anthropology theory critiques the dominant biomedical model, which often overlooks the structural factors and cultural contexts influencing health. It critiques interventions by pointing out the failures of specific examples that neglected cultural beliefs, social dynamics, and socio-economic factors. For instance, the resistance faced by smallpox eradication campaigns due to cultural beliefs and suspicion of foreign intervention underscores the importance of cultural understanding and community engagement in interventions

(Packard, 2016). Singer argues that culturally sensitive approaches are essential in order to effectively address health issues, as they take into account local beliefs, practices, and social structures.

Critical medical anthropology also emphasises the need to address power dynamics within healthcare systems and interventions. The artificial animal enclosure project demonstrates the asymmetrical relationships between global health initiatives and the communities they target. This power imbalance is evident in the neglect of social determinants of health and the prioritisation of economic considerations over public health concerns. Critical medical anthropology calls for a redistribution of power and resources within healthcare systems to ensure equitable access to healthcare and address the underlying social inequalities that contribute to health disparities.

In addition, there are significant parallels between what happened with the artificial animal enclosures, as an example of a global health intervention failure, and what James Scott argues in his book *Seeing Like a State* (1998). Scott explores the concept of legibility in statecraft and its role in the creation of a more administratively convenient society. He argues that the state's desire for legibility has resulted in a system of simplification that seeks to categorise and standardise social practices, people, and land holdings in ways that make them easier to manage from a central perspective.

Likewise, the act of grouping these animal enclosures outside the village and away from their original location in an arranged manner could be viewed as an act of simplification by the MRC and the SMOH. Such simplification has had both positive and negative effects, allowing for more finely tuned interventions such as public health measures and political surveillance, but also resulting in unintended consequences and failures of social engineering.

Scott's analysis centres on the idea of legibility, which he defines as the state's ability to "arrange the population in ways that simplify the classic state functions of taxation, conscription, and prevention of rebellion". This process of simplification, according to Scott, has been a driving force in statecraft throughout history and has resulted in a number of changes to social practices, land use, and the environment (Scott, 1998).

One of the key ways in which the state has sought to create legibility is through the standardisation of measures and practices. Scott cites examples such as the creation of permanent last names, the establishment of cadastral surveys and population registers, and the standardisation of weights and measures, all of which were designed to create a grid whereby social practices and land holdings could be centrally recorded and monitored. Similarly, the standardisation of language and legal discourse, the design of cities, and the organisation of transportation have all played a role in making society more legible to the state.

Scott (1998) argues that the organisation of the natural world has also been a key area of state intervention in the name of legibility. Agriculture, he notes, is a radical reorganisation of flora to suit human goals, and the designs of scientific forestry and agriculture, as well as the layouts of plantations, collective farms, *ujamaa* villages, and strategic hamlets, all seek to make the terrain, its products, and its workforce more legible and manipulable from above and from the centre.

These artificial animal enclosures are like abridged maps that represent only a slice of reality. They are not designed to fully capture the complexity and diversity of society but rather to make it more easily categorised and governable. In many cases, the maps themselves have the power to create the very reality they depict, through their ability to give categories the force of law.

In addition to this legibility concept, there is another important aspect to consider – the high-modernist ideology. This ideology emphasises the potential for scientific and technological progress, often relying on the expertise of scientists, engineers, bureaucrats, and other intellectuals. This component was also observed in the case of the artificial animal enclosures. The carriers of high modernism tend to see rational order in remarkably visual aesthetic terms. For them, an efficient, rationally organised city, village, or farm is one that looks regimented and orderly in a geometrical sense. This ideology is fundamentally optimistic about the possibilities for comprehensive planning of human settlement and production, often seeing rational order in aesthetic terms.

However, the carriers of high modernism, according to Scott, tend to require state action to realise their plans and often resort to miniaturisation when their plans fail. This miniaturisation takes the form of creating more easily controlled micro-orders in model cities, villages, and farms. While high modernism can be seen as a faith that borrows the legitimacy of science and technology, it is also driven by interests, particularly the interests of those who seek to create a more rational and efficient social order. This can be seen in what happened with the case of the artificial animal enclosure project, when the MRC revealed an inconsistency between the centre’s initial portrayal of the animal enclosure project as a resounding success and the subsequent labelling of it as a failure, not because of the planning of the project but because of the people involved.

Only when these first two elements – legibility and high-modernist ideology – are joined with a third element, that of an authoritarian state, does the combination become potentially lethal. This third element is an authoritarian state that is willing and able to use the full weight of its coercive power to bring these high-modernist designs into being, of which the MRC and the SMOH are typical examples. Lastly, the most fertile soil for this element has usually been times of war, revolution, depression, and struggles for national liberation. In such situations, emergency conditions foster the seizure of emergency powers and frequently delegitimise the previous regime. They also tend to give rise to elites who repudiate the past and have revolutionary designs for their people (Scott, 1998).

In addition to those of Singer, Scott, and Packard, Timothy Mitchell's book *Rule of Experts: Egypt, Techno-Politics, Modernity* (2002) provides valuable insights that can be applied to the context of the animal enclosure project and the analysis of failed health interventions. Mitchell's work examines the role of technological expertise and the exercise of power in shaping modern societies.

Mitchell argues that the application of expert knowledge and technologies is often intertwined with political and economic interests, which can influence the outcomes and trajectories of development projects. In the context of the animal enclosure project, an analysis informed by Mitchell's work delves into the power dynamics at play and examines how expert knowledge and techno-political factors may have influenced the perception of success or failure (Mitchell, 2002). According to Mitchell, experts wield significant power in shaping policies, interventions, and development projects. Their authority and knowledge can shape the framing of problems, the selection of solutions, and the allocation of resources. However, this exercise of power is not neutral and can be influenced by political and economic interests that may not align with the needs and aspirations of the affected communities.

Applying Mitchell's framework to the animal enclosure project, it is essential to critically examine the role of the MRC as a leading centre in the field of mycetoma disease and its management, not only in Sudan and Africa but in the whole world. The centre is the biggest in Sudan and Africa and has the validation of local, regional, and international governmental and non-governmental recognition. The director of the centre, as we elaborate on further in this thesis (see Chapter Three), holds a prominent position. Questions may arise regarding who defines the success or failure of a project and whose voices and perspectives are included or excluded in the decision-making process. Mitchell’s work encourages us to consider the broader sociopolitical context in which an intervention takes place and how power dynamics may influence the project’s outcomes and the attribution of failure (Mitchell, 2002).

Moreover, Mitchell’s analysis highlights the need to critically assess the assumptions and ideologies embedded within expert knowledge and technological interventions. Development projects often carry implicit biases and assumptions about progress, modernity, and the superiority of certain knowledge systems. These assumptions can marginalise local knowledge and practices, leading to a lack of cultural sensitivity and community buy-in (Mitchell, 2002). In the case of the animal enclosure project, a critical examination informed by Mitchell’s work suggests that the intervention reflected a lack of deep understanding of the local context and did not engage with the knowledge and practices of the community. It highlights that the project’s design and implementation did not respect or incorporate local perspectives, values, and aspirations.

The discussion above demonstrates the application of Nancy Krieger’s eco-social theory to the animal enclosure project. Eco-social theory, originally focused on human health, can be adapted to understand the complexities of animal welfare within an enclosure (Krieger, 2014). In this context, the theory emphasises the importance of considering social determinants and environmental exposures that impact the animals’ wellbeing.

The social dynamics within the enclosure, such as dominance hierarchies and social interactions, play a significant role in influencing the animals’ stress levels and overall health. Similarly, the quality of the enclosure’s environment, including access to natural habitats, enrichment activities, and exposure to pollutants, can directly affect the animals’ physical and psychological health (Krieger, 2001).

Moreover, the concept of structural violence, although primarily applicable to human injustices, can be analogously understood in the case of an animal enclosure project. This involves considering the power dynamics between animals and between animals and their human caretakers. Ethical implications arise from the structural design of the enclosure, the provision of care and medical attention, and the overall management, which can impact the animals’ welfare. Additionally, the eco-social lens allows for the examination of potential health disparities among animals within the enclosure, acknowledging that certain species or individuals may face differential access to resources and care based on age, gender, or specific needs (Krieger, 2011).

In the case of an animal enclosure project, the application of eco-social theory encourages a comprehensive approach to the promotion of animal welfare. By understanding and addressing the interconnectedness of social, environmental, and structural factors, the project can strive to create a more ethical and sustainable environment for the animals. Providing a space that caters to the animals’ natural behaviours and biological needs while ensuring fair treatment and access to resources contributes to environmental justice for the animals. Ultimately, this adaptation of eco-social theory helps ensure that animal enclosure projects are more conscious of the holistic wellbeing of the animals they house.

Conclusions

These observations led us to consider who or what actually failed. For the villagers, the failure of the intervention could actually be considered a successful act of resistance. It is not uncommon for people to have resisted NTD interventions, including those that involve mass drug administration for infectious diseases in various African countries (Negash et al., 2021). Some authors have indicated the refusal of treatment as a form of what Scott (1985) calls ‘weapons of the weak’. The refusal and rejection of the artificial enclosures, as well as their hybridisation using thorny materials, can also be characterised as ‘weapons of the weak’, and as an articulation of: personal identity and individual politics; life choices regarding livestock; historical and community identities; and concepts of selfhood and ethical value.

The original statement by the previous Director General of the WHO Margaret Chan about Neglected Tropical Diseases (NTDs) being "Cinderella diseases" implies they were long ignored but have now gained attention, akin to a "rags-to-riches" story (WHO, 2012b). While our study acknowledges this shift in attention, it suggests a nuanced interpretation. It reveals that although mycetoma, an NTD, has recently attracted investments (akin to the "riches" in Chan's metaphor), this attention has not been entirely beneficial. Specifically, our case study on the animal enclosure project illustrates that investments have been made in the context of mycetoma, but they have not necessarily translated into effective prevention, treatment, or improvement in the lives of those affected by the disease. Therefore, while mycetoma has ceased to be a 'Cinderella' disease in the strictest sense—no longer entirely ignored—this newfound attention has been somewhat misdirected. This re-evaluation of Chan's statement highlights the complexity in addressing NTDs and underscores the need for more targeted and effective intervention strategies (see, e.g., Charlier et al., 2017; Zanotti & Palomino-Schalscha, 2015).

This could include an awareness of the need for acts of ‘figurative translation’; or, rather, a clear recognition of diverse meanings and/or values – even within otherwise ‘shared’ expressive mediums, forms, and languages (e.g., languages could mean: national languages, English, medical language, regional dialects, etc.). This could facilitate mutual understanding, respect, and recognition, as well as reducing the perceived need for acts of resistance and other ‘weapons of the weak’.

What I observed in the study as being essential, but thus far unrecognised and not given, was a respect for different ways of life and for the values that these life choices are founded upon. To be successful, the intervention did not need to transform the perspective of the villagers *into* the perspective of the government officials, or vice versa. Rather, it needed to begin with the open facilitation of communication *between* these divergent perspectives.

This analysis of the artificial animal enclosure project failure raises a number of important questions about the role of the state in society, and the limits of centralised planning and control. It suggests that while legibility and simplification can be useful tools for government, they can also lead to unintended consequences and failures of social engineering. It suggests a need for a more decentralised and diverse approach to social organisation, and shows the unintended consequences of top-down interventions and the limitations of state-led modernisation projects, which resonate with the core principles of critical medical anthropology theory. In this sense, the failure of the animal enclosure intervention in Sudan offers valuable insights into the intricate complexities that surround global health interventions more generally. This failure not only highlights the challenges specific to mycetoma management but also brings to light the social, cultural, and political dynamics that intersect with health practices and interventions. In the following chapters of this thesis I critically analyse these complexities across different institutions and from different actors, with the aim of further contributing to the broader understanding of healthcare interventions in Sudan, Africa, and beyond.

Chapter Five

The Conceptualisation of Mycetoma and its Management at the National Level

Chapter Five: The Conceptualisation of Mycetoma and its Management at the National Level

Introduction

Recognising the failing mycetoma responses on a localised level, it was important to trace back the sources of mycetoma prevention policies and understand the strategic thinking behind them. While it was clear that there was a mismatch in perspectives between the villagers in East Sennar and their local government, there were more subtle tensions between the state and federal governments, indicating fractures between the core and the periphery, and problems with 'top-down' policies and public health responses. It is logical that I should not consider localised mycetoma responses independently of national structures, values, and norms. Thus, this chapter goes on to unravel the situation of national-level mycetoma policy, considering its development together with the influences that underpin national policy and its translation into local implementation. Before narrowing down to consider mycetoma, the chapter acknowledges national affairs and priorities during the time of this study, accounting for prominent national occurrences and events from 2011 to 2022.

The largest political shift noted in the country was the Sudanese revolution and military coup in 2019, which succeeded in removing Sudan's dictator, Omar al-Bashir, from his 30-year-long presidency. This immediately transformed the national ruling bodies and ministries across the country, with sudden and swift changes in governance and leadership across leading agencies and institutions (Shamsuddin Bolatito, 2019). Emerging out of constant civil war, extreme economic fragility, and years of a corrupt autocracy, the newly democratised transitional government affirmed its commitment to national wellbeing and health security, guided by the Sustainable Development Goals (SDGs), including 'ending the epidemics of HIV, tuberculosis, malaria and neglected tropical diseases' (SDG 3.3). Having been intensely reconfigured over only a couple of months, there is little to no evidence on how the new Ministry of Health currently produces disease-management policies for NTDs.

Historically, it is well established that NTD control programmes have operated globally relatively autonomously from formal health systems (Marchal et al., 2011); for example, elements of health system strengthening are *parallel* to vertical NTD responses, with many considering their progression independent. In some contexts, this may be attributed to the need for service delivery despite generalised health system failures, necessitating the use of alternative delivery systems for treatment and prevention, especially in vertical programmes such as mass drug administration for infectious disease prevention (Samsky, 2012; Utzinger et al., 2009). However, in some cases separation has occurred because of the highly specialised expertise required to both research and treat particularly rare and complex NTDs, which are known for their unique drivers and infection mechanisms. Mycetoma is an example of these rare and complex NTDs, which often demand that vertical programmes are synchronised with health system responses and learnings (Zijlstra et al., 2016). Considering Sudan's health system and its aforementioned turbulence in leadership, it is important to understand how this translates to the mycetoma response across multiple levels, including the roles of government, academia, and the private sector in planning and mobilising the response. This chapter draws on in-depth interviews with key stakeholders from government and private organisations dealing with mycetoma in Sudan, to offer reflection on the potential challenges to mainstreaming mycetoma treatment within the Sudanese national health system.

Sudanese health policy and the health system

Policies and plans in Sudan are produced at three levels: federal, state, and district. There is one Federal Ministry of Health (FMOH) and eighteen State Ministries of Health (SMOH). The federal level is responsible for the provision of nationwide health policies, plans, strategies, overall monitoring and evaluation, coordination, training, and external relations. The state level is concerned with the state's strategies – based on federal guidelines – as well as with the itemised funding allocation and implementation of federal plans in coordination with district-level leadership.

Health services provided in Sudan follow the classic three-level structure of primary, secondary, and tertiary healthcare (see Figure 23). Primary healthcare is the first encounter for most people seeking public medical services: it includes health stations, dispensaries, primary healthcare units and health centres, with most referral mechanisms directing people from smaller facilities towards health centres. This line of primary care is almost entirely provided for by the public sector as a dimension of governmental public services. Both public and private sectors work together in the provision of the secondary and tertiary lines of care. Health services in Sudan are provided by the federal and state ministries of health, military medical services, the police service, universities, and the private sector. There has also been an increase in the involvement of non-profit organisations in health programming, which function in coordination with the FMOH (For further information please see Ebrahim et al., 2018).

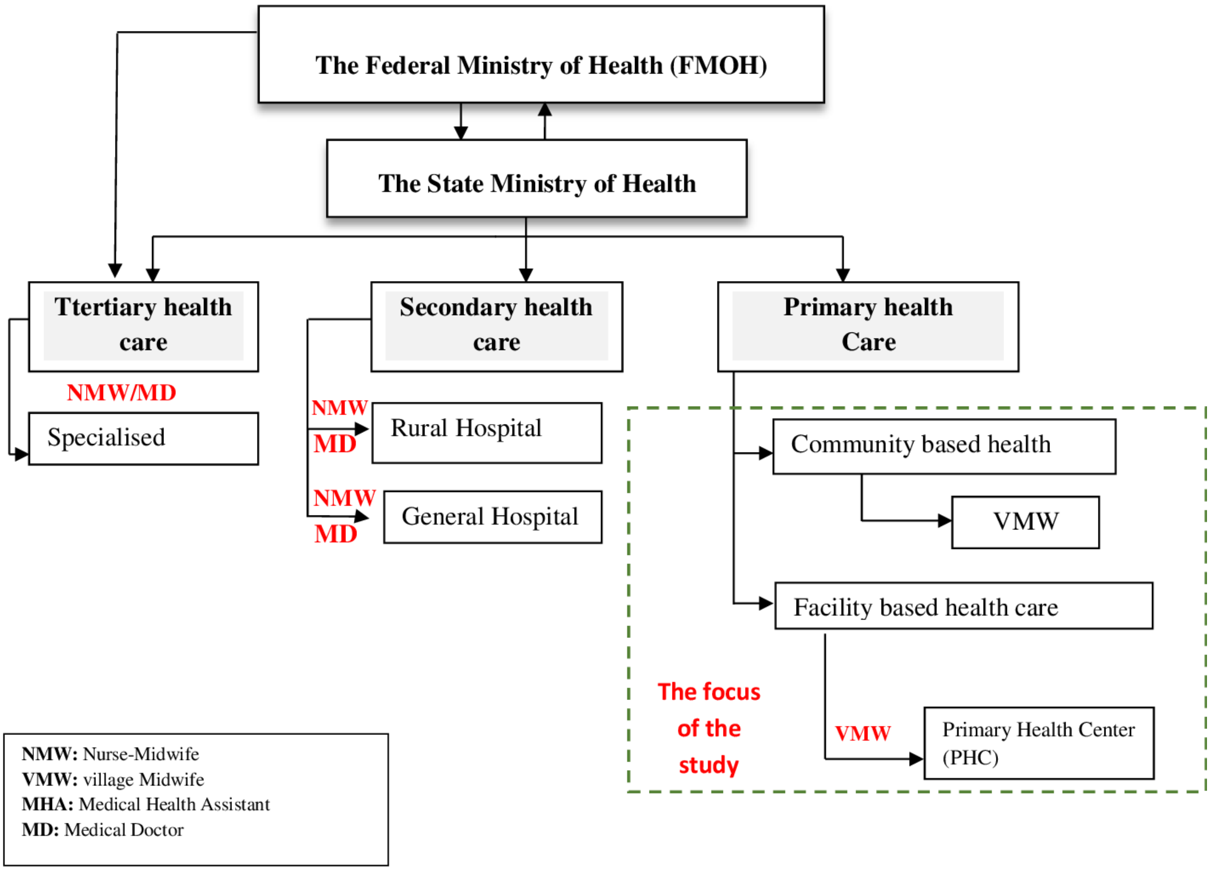

Figure 23: Providers of health services under the federal and state ministries of health in Sudan.

International and civil conflicts have long been recognised as a primary reason for healthcare decline (Osman et al., 2021). This disruption of the health system takes the form of a defunded – and therefore deteriorating – health infrastructure, with neglected needs of maintenance and repair. This section considers the current health services and provisions available to the Sudanese populace that may have a role in mycetoma control.

Mycetoma's being a disease of poverty, there was a need to recognise any existing safety nets that people living with mycetoma are able to access. The National Health Insurance Scheme, introduced in the mid-1990s, covers about 8% of the population, most of whom are government employees (75%), the remaining being poor families (6%), families of people in the army (3%), and students (2%). It is important to note that most government employees and military families are automatically enrolled in the scheme, and that it is available to all students at little to no cost compared with the rest of the population.

Understanding national mycetoma policies, their strengths, and their weaknesses is key to controlling the disease. As a disease that is fuelled by social determinants and confined to certain sub-populations, an effective mycetoma eradication strategy in Sudan should ideally consider prevention and treatment bottlenecks at all levels of an ecological model, especially including those policies that were specifically tailored for mycetoma, and how they came into being. Assessing the limits of Sudanese mycetoma policies – and reviewing them alongside the previously mentioned community- and individual-level restraints –allows for a more holistic treatment of the disease in Sudan. Understanding the policies and politics surrounding mycetoma is not just useful in controlling the illness, it is obligatory. Without adequate buy-in and attention from policymakers, little to no resources will go towards controlling this already neglected disease.

Additionally, understanding national mycetoma control strategies may also be useful to the Ministry of Health for the formation of complementary health policies: for example, epidemiological studies have thoroughly described the increased burden of synergistic bacterial infections with mycetoma (Ahmed et al., 1998); cohort studies have also explored mycetoma’s strong links to family history and its direct impacts across childhood and neonatal health indicators; and healthcare facilities have noticed links to informal treatments and traditional healers through mycetoma patients as an additional trend (Ezaldeen et al., 2013a). Mycetoma control is highly related to other health foci, a few of which include bacterial disease control, child health, and alternative medicines. Policies that may decrease mycetoma’s burden could potentially have positive ripple effects across other disease control indicators as well, thus optimising the use of resources accordingly. This reaffirms that the policymaking process needs to be well understood.

I aimed to understand the health policy situation in Sudan in relation to mycetoma using the policy analysis framework proposed by Walt and Gilson (1994). The framework suggests that in order to plan for any health reform it is crucial to pay attention to the health policy ‘environment’, particularly in the developing country context. Walt and Gilson developed a well-known framework to explore the policy environment, which models the interplay between four concepts: context, content, actors, and process. One important virtue of this model lies in its distinguishing structure and process and making explicit the interplay of actors and interests within specific political−institutional contexts.

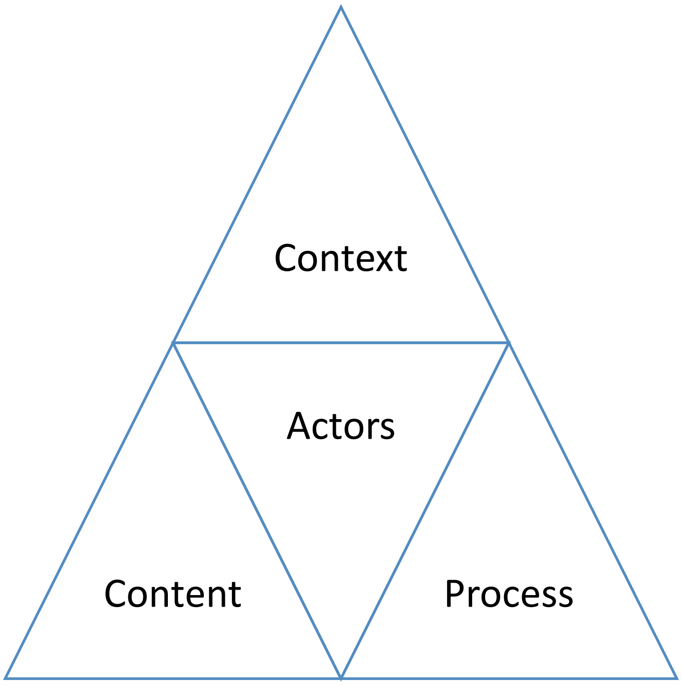

Figure 24: Walt and Gilson's policy triangle framework (Buse et al., 2016a).

Findings

As a structure that considers not only the four dimensions of health reform (context, content, actors, and process), Walt and Gilson's (1994) policy triangle framework was used to analyse the data (see Figure 24). The four categories of context, content, actors, and process correspond broadly to the 'why, what, who, and how' respectively of health policy analysis; these categories have each been defined in the Methodology section of Chapter Three. Thus, the results outline the emerging findings across these four dimensions, building an understanding of the national needs and how they have materialised through mycetoma-associated policies (Faraji et al., 2015).

Context

The Republic of the Sudan is located in the north-east of Africa and is the third-largest African country in terms of geographical range after Algeria and the Democratic Republic of the Congo. In 2011, under the terms of the Comprehensive Peace Agreement, the Republic of South Sudan took shape in what were formerly known as the southern Sudan states. After the separation, the Sudan lost 75 per cent of its oil resources and almost half of the country's revenue. Consequently, the Sudanese economy suffered losses from the withdrawal of oil revenues, and the annual percentage growth rate of its gross domestic product (GDP) decreased from 7.8% in 2008 to 3.1% in 2014 (Ebrahim et al., 2018). The current estimated population of Sudan is 41,727,150 according to a United Nations report in the first month of 2017 (Ebrahim et al., 2018). The total life expectancy for males and females at birth was estimated at around 62 and 66 years respectively (Ebrahim et al., 2018). The under-five child mortality rate was 77/1,000 in 2015 compared with 128/1,000 in 1990, and the maternal mortality ratio was 360/100,000 in 2015 compared with 720/100,000 in 1990. Sudan is considered a lower-middle income country, with 47 per cent of the population living below the poverty line. In addition to the excessive burden of communicable diseases such as malaria, tuberculosis, and schistosomiasis, Sudan is predominantly susceptible to non-communicable diseases, and to natural and manmade disasters. Drought, flood, internal conflicts, and outbreaks of violence are relatively common, and bring about a burden of traumatic disease and a demand for high-quality emergency healthcare. Sudan is a federated republic with powers devolved to its 18 states and 184 localities. Its total population is 36 million, spread sparsely, and is growing annually by 2.5 per cent (Ebrahim et al., 2018).

Content

There are no official published policies regarding mycetoma and its management in Sudan. In the absence of a precise case definition and field-friendly diagnostic tools, mycetoma is not a well-understood disease. For decades mycetoma has not been a priority for the Federal Ministry of Health (FMOH) of Sudan. It was only in 2015 that the Department of Communicable and Non-Communicable Disease Control (CNCDC) of the FMOH initiated a policy formulation for NTDs and malaria at the national level. However, to date there has been no published policy in this regard from the FMOH. Although there exists an official commitment to formulate a policy regarding NTDs, our key informant interviews reveal that health ministry stakeholders do not always align with this commitment. For example, one high official of the FMOH held the opinion that, although disabling, NTDs such as mycetoma are not fatal like many other diseases that have clear case definitions and incidence and prevalence rates, so they do not deserve the same level of attention. He said:

> Mycetoma indeed is a devastating disease and should be treated but I don’t think it is as important as tuberculosis. And if I have to choose between TB or mycetoma in terms of prioritisation, I will choose tuberculosis. … for our department mycetoma is not our priority.

(Key Informant, FMOH)

Political instability resulting in a quick turnover of senior leadership roles within the FMOH may also have contributed to the lack of focus on mycetoma and to rapidly shifting priorities that urge for 'quick-return' projects that are appealing to government leadership, donors, and national civil society. The global focus on other conditions such as TB, malaria, and HIV was reflected through a massive increase in their funding nationally, which, for example, encouraged healthcare workers to focus in these areas, where career opportunities were better (De Jongh et al., 2014).

The only policy guidelines that were available on mycetoma were prepared by the MRC, which was established in 1991 under the umbrella of the University of Khartoum. It was set up to provide medical care for mycetoma patients, and research and education in various aspects of mycetoma. The MRC is a globally recognised centre dedicated exclusively to mycetoma. A document entitled 'Mycetoma policies and management guidelines for service provision and essential good clinical practice 2017' drew on 25 years of experience in the management of mycetoma patients at the centre. The document set out three main strategic objectives for tackling mycetoma: improving access to treatment, ensuring high-quality service, and bridging the knowledge gap. The following excerpt from the document indicates the priority areas for mycetoma:

> The most priority area for research is the disease mapping and the estimate of prevalence and incidence worldwide … Also, improvement of the cultural and molecular techniques to determine the infective agents as well as serological tests for diagnosis and follow-up of patients … Improvement of mycetoma drug's efficacy is strategic for improvement of mycetoma patients' treatment outcomes. Clinical trials to adopt new therapy for treatment of mycetoma are the best approach for the time now.

(MRC Healthcare Worker, 2018)

It should be noted that the MRC guidelines are based on experience of treating only those patients who reach out to the MRC. Furthermore, according to the MRC their focus is on certain specific geographical regions, especially where the disease is endemic. Moreover, these guidelines have not been published in a peer-reviewed forum and there is no indication of government endorsement of these guidelines.

Actors

In Sudan, the MRC is the main actor dealing with mycetoma-related issues. The MRC is also one of the major global actors for mycetoma. It is the only specialised facility to provide guidelines, strategies, and policies regarding mycetoma patients. At a glance, it would seem obvious that both national and international agencies would be interested in mycetoma work through the MRC in Sudan, as it is seen not only as a research institution but as an ‘entry point’ to eliminating a debilitating illness that is confined to only a handful of countries (including Sudan). For example, the FMOH donates free medication to the MRC, which is then dispensed to individuals affected by the disease who attend the MRC clinic. Certain individuals also play a role as key actors in promoting mycetoma issues in Sudan. As one of the key informants stated:

> He [the head of the MRC] is influential … He influences the power map of mycetoma. However, earlier Professor Mahgoub also did lots of research in medical mycology for nearly 50 years on mycetoma. People do not remember him much nowadays.
>
> (Key informant, FMOH)

On the other hand, there are also a variety of international actors in the field of mycetoma in Sudan, all of whom work through the MRC, as highlighted in Figure 25 below. For example, the Drugs for Neglected Disease Initiative (DNDi) supports the MRC in conducting randomised control trials to test new mycetoma therapies, and the Japan International Cooperation Agency (JICA) provides artificial limbs for patients through collaboration with the MRC. As indicated in the findings from East Sennar, detailed in Chapter Six, the MRC also receives multiple donations from private companies and it is not unusual for them to collaborate for service delivery; for example, as its social accountability activity, an engineering company donated and assisted with the installation of 72 modern animal enclosures for villagers in mycetoma-endemic areas, free of charge, to improve village hygiene and reduce contact with animals and their excreta (Bakhiet et al., 2018). The MRC has developed an international academic network and established partnerships with several international institutes, including various established higher education institutions that have contributed to the supervision and coordination of research around mycetoma; my PhD research, for example, has been coordinated by a collaboration between the MRC, the Brighton and Sussex Medical School

(BSMS), and the National Institute of Health Research (NIHR) in the United Kingdom. Other academic partners include the Erasmus MC, Erasmus University Rotterdam in The Netherlands, and the University of Tours in France, as indicated in Figure 25. These growing partnerships support research and training activities including postgraduate studentships.

Figure 25: Shows the diversity of global and regional actors working with the MRC on mycetoma control in Sudan. This diagram indicates 'active' partnerships in January 2021.

Process

The process of policymaking, in other words the way in which policy is brought forward and implemented, depends on the interests of and the interrelationships between the actors involved. Our study reveals that mycetoma is not considered as a priority by the FMOH. The government and other donors that often grant funding and resources allocated for mycetoma do not provide these resources to the FMOH, but rather issue them directly through the MRC. As a result, the FMOH is left with minimal power and this creates a tension between the MRC and the FMOH.

Key informant interviews with an FMOH representative suggest that some FMOH staff have reservations about the approach the MRC takes regarding mycetoma treatment and prevention. One key informant from the FMOH said:

> What is available at [the] MRC are facility-based cases – they do not have the prevalence nor the incidence of the mycetoma. I cannot blame the MRC because

> they are taking mycetoma from a research perspective. … as a result, they seek to centralise services in the centre. Patients from all over Sudan approach [the] MRC for advice and medical care instead of having the same services decentralised in the nearby primary medical facilities.

(Representative of the FMOH)

Some of the FMOH stakeholders were also worried about the MRC being the only organisation that represents Sudan in respect of mycetoma to international actors. According to one FMOH representative:

> Now everyone wants to work in mycetoma – not only from Sudan but also from outside. Whoever is interested in mycetoma goes directly to [the] MRC. I don't think [the] MRC should be the only representative of the country in regard to mycetoma.

(Representative of the FMOH)

Another key informant from the FMOH expressed concern about the cooperation they receive from the MRC:

> We invite them in our meetings, but MRC representative does not always attend. It would have been better if we could have them from the starting of any project. MRC has international expertise in mycetoma, and we need them from the start. But maybe they have different idea.

(Representative of the FMOH**)**

On the other hand, researchers from the MRC expressed frustration about a lack of interest in mycetoma from the FMOH. The MRC representative said:

> I don't know whether [the] FMOH is considering mycetoma as a priority or not. I cannot see a clear programme for mycetoma, but they have a visible programme for TB, and they also have a clear programme for malaria, but there is not a clear programme for mycetoma; there is some activity by [the] FMOH towards eradicating other diseases. Where are these activities when it comes to mycetoma?

(Researcher, MRC)

Another MRC representative stated:

> I don’t have a direct relationship with the Ministry, but they have a presence in our activity; for example, in the conference we invite them, so they are present. [The] MRC does not depend on the FMOH; we try to find funds without depending on [the] FMOH. [The] MRC actually does not get enough support from [the] FMOH. When you approach the FMOH, they talk about other outbreaks.

(Researcher, MRC)

Although it appears that there is a communication gap between the MRC and the FMOH, the MRC works closely with the Sennar State Ministry of Health (SMOH), Sennar State having some of the highest rates of mycetoma in Sudan, where there is an epidemic of this disease and some specific interventions have been carried out. There is a specialised centre for mycetoma patients in Wad Onsa village in East Sennar, acting under the direct supervision of the SMOH in collaboration with the MRC, which provides medication, counselling, and a referral centre for patients from Wad Onsa village.

Discussion

The literature states that power influences policy processes and outcomes in a multitude of ways, such as through the relationships between actors, the development of trust, and the manner in which policymakers act with the tactical exclusion of certain issues or people (Hong & Sullivan, 2013; Mwisongo et al., 2016). Collins et al. have further stated that “Policy formulation and implementation take place in a context which gives explanatory and historical meaning to that policy” (Collins et al., 1999). For Sudan, the long-lasting internal conflict and civil war have undoubtedly affected the overall health policy environment of the country. Several disruptions – including the previously mentioned years of civil warfare and conflict, a nationwide revolution, and a presidential coup – have shocked and chronically weakened the health system. Since the military-led government was formed in 1993 and the subsequent civil war with the – now independent – South Sudan, the health system has taken a form that is characterised by medical pluralism with multiple categories of health providers, in which the private sector covers the vast secondary- and tertiary-level health provision. The mere shift to private sector domination signifies the deterioration of the Sudanese public health system. It was unlikely that mycetoma prevention and treatment would have been an exception; thus, this discussion highlights the context in which mycetoma policies and strategies now sit.

The MRC

It is evident that among the actors within the field of mycetoma in Sudan the MRC is the most powerful. The MRC leadership have global connections, and many international actors work directly with the MRC bypassing the FMOH. The MRC receives substantial international funding and collaborates with various UN organisations and international universities. It is apparent that this relative exposure and importance of the MRC creates a tension among FMOH officials.

Arts and Tatenhove’s framework for policymaking conceptualises power as having three layers: relational, dispositional, and structural power (Hong & Sullivan, 2013). According to this framework dispositional power results from agents being placed in certain positions that render them more influential than others. We may say that the MRC has dispositional power in Sudan through its greater connectivity with international stakeholders and better access to resources. While studying health policy in Africa, Azza et al. commented that dispositional power is the most complex form of power expressed both overtly and covertly. With this form of power, resources, knowledge, and capacity have an influential role; it is also open to abuse if there are imbalances in the share of negotiation capital among the actors (Mwisongo et al., 2016). It appears that the source of the dispositional power of the MRC is also linked to the fact that they have more connections to international bodies such as the WHO and other multinational companies. The MRC’s legibility to supranational institutes like the WHO and others adds to the complexity of policymaking processes on mycetoma in Sudan.

Further, it appears that the MRC is the sole organisation active in various kinds of mycetoma interventions, including the formulation of guidelines. It appears that although the MRC works in collaboration with Sennar State, there is a lack of coordination between the MRC and the FMOH. A lack of coordination between different stakeholders has been identified as a barrier to policymaking in other low- and middle-income countries as well. However, it is clear that the lack of coordination between the FMOH and the MRC in Sudan is determined by power (Collins et al., 1999).

This lack of coordination could also be linked to the working environment around the MRC, since the MRC was established as a surgical clinic under the umbrella of the Soba teaching hospital, which is affiliated directly to the University of Khartoum, the first medical university in Sudan and the top-ranked medical university in the country for many years. The MRC is also considered to be one of the top research centres in Sudan, the only substantial centre in the world to specialise in treating mycetoma disease, and the only WHO Collaborating Centre on Mycetoma in Sudan. The centre is also recognised globally as a world leader and an authoritative advisor in mycetoma management and research (MRC, 2022).

The FMOH

This study also revealed that mycetoma is not a priority health issue within the FMOH agenda in Sudan and that there is no policy or strategy in this regard. The only policy document on mycetoma available in Sudan was prepared by the MRC; this is, again, unpublished and does not have national endorsement. We argue that the absence of a national mycetoma policy in Sudan is influenced by three key factors: the process of public health prioritisation, the issue of coordination, and the role of power.

The FMOH in Sudan prioritises their agenda based on epidemiological considerations and mobilises their resources accordingly towards conditions such as TB and malaria, which are established public health priorities. Since the prevalence and incidence rates for mycetoma in Sudan are unknown, mycetoma does not receive the funding or attention it requires towards its elimination. It is also likely that due to the political turmoil there have been changes in national leadership, which have meant that the health ministry continued to maintain the traditional health agenda, including controlling TB and malaria, without including new diseases such as mycetoma.

Although the epidemiological indicators for mycetoma in Sudan have not been estimated, other studies have shown that Sudan has the highest burden of mycetoma in comparison with any other country globally. In addition to the physical burden, there is evidence that NTDs including mycetoma bring enormous psychosocial suffering to affected people (Carson, 2011); however, psychological and sociocultural responses are not captured through quantitative epidemiological studies.

Coordination between the FMOH and the MRC

Building on the organisational and institutional dynamics presented throughout this research, this sub-analysis spoke to the interrelationship between the MRC and the FMOH, which has proven to be rather complex. While the FMOH acknowledges the achievement of the MRC and allocates government resources to them, comments from the government representatives imply that there is a hidden tension among government officials regarding the power and independence that the MRC enjoys. There is also a concern from the FMOH that the MRC tackles issues from a research perspective, rather than from a public health perspective. On the other hand, MRC researchers doubt the commitment of the FMOH in tackling mycetoma. This subtle power dynamic is likely to hamper the process of policy- or strategy-making on mycetoma in Sudan (Hong & Sullivan, 2013; Mwisongo et al., 2016).

It is obvious that no single factor can fully enable or constrain policymaking and that factors that may facilitate or constrain policymaking must always be contextualised in place and in time. In order to create an enabling environment for developing policy regarding mycetoma it is important not only to have clear epidemiological knowledge of this disease but also to acknowledge the suffering of people affected by mycetoma, which cannot always be captured through epidemiological indicators. However, most important is to ensure coordination between the existing power of the MRC and the FMOH – the two vital health actors in relation to mycetoma in Sudan. This can only take place if the power imbalance between the stakeholders can be neutralised.

Chapter Six

The Role of Traditional Healers in Mycetoma Management in Wad Elnimear Village

Chapter Six: The Role of Traditional Healers in Mycetoma Management in Wad Elnimear Village

Introduction

After exploring the situation of mycetoma at the macro level, in this chapter I examine mycetoma at the meso level (Zaman et al., 2020b). In the sections that follow, I highlight the knowledge and services provided by traditional healers, and the management pathways that mycetoma patients and their families are obliged to navigate. One key area of inquiry within critical medical anthropology that is addressed in this chapter refers to the question of how traditional healing practices are integrated into mainstream biomedicine (Singer, 2015).

Medical pluralism, also known as the utilisation of multiple treatment modalities (Leslie, 1980), occurs in circumstances where both biomedical and traditional healers are available to individuals (Sundararajan et al., 2020). There are several treatment systems for health and illness in Sudan, incorporating healthcare delivery strategies that consist of both traditional and modern medicine. The issue of where people choose to seek care is complex; it touches upon a range of socio-economic and cultural dimensions of illness, from trusting medical providers and public systems to affordability and family norms. Some LMICs have formalised parallel traditional and biomedical treatment streams and have tried to bridge the community-level gap by recruiting religious leaders and community healthcare workers into the health system. Although there are material and emotional foundations to health-seeking behaviour, evidence highlights that an individual's interaction with alternative healthcare sectors depends largely on the ways in which the ill person perceives their health problem, and sometimes most importantly, how it is perceived by relatives and/or close friends (Tabi et al., 2006).

'Traditional medicine' is known by many names, including: ethnomedicine, native healing, folk medicine, or complementary and/or alternative medicine. It is an ancient and culture-bound method of healing that humans have used to cope and deal with various diseases – although it is abundantly evident that illness is only one among many other reasons for people to go to traditional healers (Abdullahi, 2011).

Healthcare systems partly originate, and then develop, in tandem with the health/healthcare views of the people using these systems, which are in turn affected by culture, beliefs, and values. Healthcare providers' understandings of their patients' healthcare beliefs, values, and preferences are an essential feature of patient-centred care (Kennedy et al., 2018). Through experience and socialisation, people demonstrate health behaviours that are reflective of personal and group development. Perceptions of health and disease, the expression and interpretation of symptoms, and the types of healthcare available all guide these health behaviours. Globally, among most cultures, including the people of Sudan, there is a retention of indigenous (i.e., 'traditional') health beliefs. Even though people in Sudan may accept modern scientific medicine, they retain traditional concepts to give meaning to their health experience (Tabi et al., 2006).

The term 'traditional medicine' gathers a variety of beliefs, practices, and stories of ancestral origin, which are adhered to by large groups within the populations of different countries throughout the world. Traditional medicine is itself a medical system that can diagnose, treat, and prevent diseases of different aetiologies (Stekelenburg et al., 2005). The study of traditional medicine provides better understanding of how cultures shape knowledge of anatomical and physiological function, body image, and the meanings attached to symptoms. It describes how cultural socialisation practices influence the health and illness behaviours of males and females, and recognises the beliefs and practices, values, knowledge, and traditions framed by the culture and worldview of a people (Safi, 2017). It has been argued that traditional healers can play a positive role in promoting healthcare in communities where their methods are culturally accepted and holistic, as compared with those of 'modern medicine'. Community, cultural, and personal self-esteem can be stimulated because people use their own, instead of foreign, modalities of care to maintain or improve health (Stekelenburg et al., 2005). Since the use of traditional healers was (and still is) so widespread, cooperation with them could contribute to improving access to healthcare (Maclean & Bannerman, 1982). More than 80 per cent of the people in sub-Saharan Africa have traditional healers in their treatment pathway (Stekelenburg et al., 2005; Sundararajan et al., 2020).

A large sector of the Sudanese population uses traditional medicine to meet their primary healthcare needs, though this dependence takes different shapes and forms across ages, tribes, geography, and faiths (Safi, 2017). In addition to being accessible and affordable, there are many overlaps between traditional medicines and local/inherited beliefs – this becomes more pronounced in rural settings. While some may have the luxury of choice, others do not; in many parts of the country traditional medicine often provides the only available health service to the population (Safi, 2017).

The term ‘traditional medicine’ can misleadingly imply a homogeneous group of medical practitioners, whose practice is often seen as irrational and timeless (Sorketti et al., 2010). However, even though ‘traditional medicine’ is no longer relevant as an analytical category, as West and Luedke astutely note, it remains very much in currency as a ‘folk category’, which is used by a variety of people, including healers themselves (Marsland, 2007). Both traditional and modern medicine are integral components of the healthcare delivery systems of many countries (Kwame, 2021). In countries with scarce medical resources, with clashing transitions between modern and ancient health cultures, the approach to healthcare is often based on a person’s own understanding of their health, life, and being (Tabi et al., 2006). In 1978, at the Alma Ata conference on Primary Health Care (PHC), the World Health Organization (WHO) recommended cooperation between traditional healthcare systems and the healthcare system offered by Western, sometimes so-called ‘modern’, medicine (Maclean & Bannerman, 1982; Stekelenburg et al., 2005). Later, comparable recommendations for cooperation were presented to fight major diseases in sub-Saharan Africa, such as sexually transmitted diseases (STDs), including HIV/AIDS, and tuberculosis (Freeman & Motsei, 1992; Stekelenburg et al., 2005).

According to the WHO definition, a traditional healer is a person who is recognised by the community in which he/she lives as being competent to provide healthcare by using vegetable, animal, and mineral substances and certain other methods based on the social, cultural, and religious background as well as on the knowledge, attitude, and beliefs that are prevalent in the community regarding physical, mental, and social wellbeing and the causation of disease and disability (Birhan et al., 2011; Stekelenburg et al., 2005).

For Helman, the term ‘healer’ refers to all those who, either formally or informally, offer advice and care for those suffering from physical discomfort and/or psychological distress, or who advise on how to maintain health and a feeling of wellbeing (Helman, 2007).

Traditional medicine is very popular in most regions of sub-Saharan Africa. According to the WHO, in Ghana there is one traditional healer per 200 people while there is only one university trained doctor for 20,000 people (Tabi et al., 2006). It is estimated that traditional healers cover 80–90 per cent of healthcare in Africa and that 80 per cent of the global population seek traditional healers to meet their primary healthcare needs (Kwame, 2021; Labhardt et al., 2010; Oyebode et al., 2016). As Labhardt et al. list them, the most frequently cited reasons for seeking a traditional healer are as follows: consistency with local cultural values and beliefs; a better healer–patient relationship; proximity; and lower cost compared with Western healthcare facilities (Labhardt et al., 2010). Given the significant number of people seeking care from traditional practitioners, numerous health programmes have tried to involve traditional healers, especially within HIV/AIDS education and patient care. However, the realisation of such programmes has proved to be an area of argument: some researchers view it as a difficult task to establish collaboration between traditional healers and westernised medicine (Kayombo et al., 2007; Labhardt et al., 2010); while others speak about the suitability of the traditional healers to further educate about Western medicine and collaboration (Heinzerling, 2005).

In the last decade, there has been a global increase in traditional and complementary/alternative medicines in both developed and developing countries. The reasons for this in developing countries are frequently given as: cultural acceptability; perceived efficacy; affordability; accessibility; and psychological comfort. Other factors include: the inaccessibility of modern health services in terms of geography, cost, or time, and a shortage of well-trained modern health professionals (Birhan et al., 2011).

The relationship between biomedical medicine and traditional healing practices is complex and has long been a topic of interest within medical anthropology (Kleinman, 1983; Waldram, 2000; Zank, 2017). In many parts of the world, traditional healing practices coexist alongside Western biomedical practices, and people often turn to both forms of healing depending on their illness, cultural beliefs, and socio-economic status. However, the relationship between these two systems of healing has not always been harmonious, and in many cases, biomedical Western medicine has come to dominate traditional healing practices. In this chapter, I examine how the biomedical Western treatment system, represented by actors such as the MRC, has come to neglect the traditional healer treatment system from a medical anthropological perspective. I also discuss how the MRC views the traditional healer system and how understanding this power dynamic can help in improving health and illness. In addition, I challenge the commonly existing notion that traditional healers are the main source of delay in the management of mycetoma, and argue instead that they are the only option for low socio-economic groups. Finally, I explore why mycetoma patients seek traditional healers as a first choice of treatment.

Understanding the power dynamic between biomedical Western medicine and traditional healing practices is essential in improving health and illness in mycetoma disease. One of the key steps in addressing this power dynamic is to recognise the value and importance of traditional healing practices in the treatment of NTDs such as mycetoma. Traditional healing practices have been used for centuries, even before the existence of biomedical medicine, to treat a wide range of illnesses, and they often take into account local beliefs and values.

By recognising the value of traditional healing practices, Western biomedical practitioners can work with traditional healers to develop effective and culturally sensitive treatment plans for mycetoma. By supporting research that is grounded in local knowledge and practices, this chapter hopes to begin to build a more equitable and collaborative approach to healthcare in mycetoma and other NTDs. This can help to ensure that local knowledge and practices are recognised and valued in the development of effective treatment strategies for mycetoma.

In the case of most NTDs, traditional healers are a crucial component of the healthcare-seeking trajectory for afflicted individuals (Banks et al., 2016; Cohen et al., 2007; Elkheir et al., 2020a; Kwedi Nolna et al., 2020; Poudyal et al., 2005; Steinhorst et al., 2021); for those afflicted with certain NTDs, they actually constitute the first healthcare encounter (Mendizábal-Cabrera et al., 2021; Poudyal et al., 2005).

Due to their culturally focused approach towards health promotion and disease prevention, traditional healers are recognised as key players in the healthcare for NTDs and hence many studies suggest collaboration between traditional healers and westernised medicine (Steinhorst et al., 2021). Furthermore, many countries have launched collaborations between traditional and westernised medicine in the field of NTDs. Some of these initiatives train the traditional healers to give them basic knowledge about various illnesses and encourage them to refer patients to their westernised medical partners without delay; this has been seen with trachoma (Poudyal et al., 2005), and with human African trypanosomiasis (HAT) (Kwedi Nolna et al., 2020). In the case of Buruli ulcer, patients are open to collaborating with healthcare workers; however, healthcare workers have been less inclined. Given the patients’ beliefs about Buruli ulcer and the discrimination involved, collaborations between communities, and both traditional and biomedical providers are vital to improving Buruli ulcer management and reducing stigmatisation (Geneva, 2019).

Little light has been shed on the relationships between traditional healers and the treatment of mycetoma both globally and nationally in Sudan. There are few recent studies about traditional healers; both contemporary studies were quantitative in nature, and were conducted in Sudan within the MRC (Elkheir et al., 2020a; Ezaldeen et al., 2013b; Fahal et al., 2014; Kunna et al., 2021a).

Traditional medicine contributes significantly to the treatment of mycetoma in Sudan. According to Kunna et al. (2021b), almost all of their study participants (389) had visited a traditional medical healer at some stage of their journey with the disease, and for 66 per cent of them the traditional healer was the first point of contact (Kunna et al., 2021b).

In all of the studies done by staff working at the MRC, traditional healers have been viewed as a major contributor to the delay in the patient's seeking biomedical treatment through the MRC (Elkheir et al., 2020a; Ezaldeen et al., 2013b; Fahal et al., 2014; Kunna et al., 2021a); from among these studies, only one mentioned the importance of collaboration with traditional healers, and it spoke of this collaboration being utilised mainly to accelerate the rate of referral to the MRC (Kunna et al., 2021b). One study even suggests that the choice of an alternative treatment option such as herbal and local medicinal plants over modern drugs is due to the disappointing cure rate of itraconazole and the cost of the drugs to treat the infection (Van de Sande et al., 2017).

This chapter starts from the conviction that understanding and creating synergies between these parallel health systems is necessary; I explore Wad Elnimear villagers' perspectives regarding traditional healers and their health-seeking pathways with mycetoma.

Results

Traditional healers play a major role in managing mycetoma in the study site. Most of the individuals who encounter mycetoma visit a traditional healer during their journey with the disease. Patients' decisions to seek care from both traditional healers and biomedical health facilities were associated with dissatisfaction regarding the outcomes of the specific treatment modalities. Most of these patients reported seeking every possible treatment modality; these often included every sheikh and traditional healer, and even westernised medicine, because the patients were desperate and not satisfied with the treatment outcome of their previous treatment system. The majority of the mycetoma patients dealt with traditional healers during one or more stages of their journey with the disease, and some of those patients visited more than one healer. I took the photo shown in Figure 26 during 'Alholia', a large gathering for religious leaders in East Sennar State; people tend to travel long distances to attend this event, some coming for *Duaa* ('seeking a cure from Allah') in the hope of finding relief from their medical conditions. It was also attended by some government officials, as a substantial social gathering.

Figure 26: ‘Alholia’, a large gathering for religious leaders in East Sennar State.

Treatment-seeking pathways

Sequential and simultaneous health seeking are two approaches that are used by patients to seek healthcare services. Sequential health seeking occurs when a patient visits more than one healthcare provider in a stepwise pattern, with each provider visited after the previous one fails to provide a diagnosis or effective treatment (Moussavi et al., 2018). In contrast, simultaneous health seeking occurs when a patient visits multiple healthcare providers at the same time, seeking diagnoses and treatment from all of them (Chomi et al., 2014; Kamaldeen et al., 2019).

Sequential health seeking is common among patients with chronic illnesses, such as diabetes and hypertension, who may need long-term care (Moussavi et al., 2018). A study by Moussavi et al. (2018) found that sequential health seeking was prevalent among patients with diabetes in Iran, with patients seeking care from both traditional and modern healthcare providers. However, sequential health seeking can lead to delayed diagnoses and treatment, as patients may spend a significant amount of time seeking care from multiple providers before receiving effective treatment.

Simultaneous health seeking, on the other hand, is common among patients seeking second opinions, or with those who lack confidence in the diagnosis provided by a single healthcare provider (Kamaldeen et al., 2019). A study by Kamaldeen et al. (2019) found that simultaneous health seeking was prevalent among patients with chronic pain in Nigeria, with patients seeking care from multiple healthcare providers, including traditional healers, in an attempt to find relief. However, simultaneous health seeking can lead to fragmented care and increased healthcare costs, as patients may receive conflicting diagnoses and treatments from different providers.

Different pathways were recognised among Wad Elnimear villagers regarding mycetoma management. Some individuals go directly to the traditional healers and remain with them exclusively; some are then referred to biomedicine by the traditional healer, while some are probably never referred. A section of the patients seeks help from both biomedicine and traditional healers and some patients return to traditional healers after seeking treatment in westernised centres (see Figure 27, below).

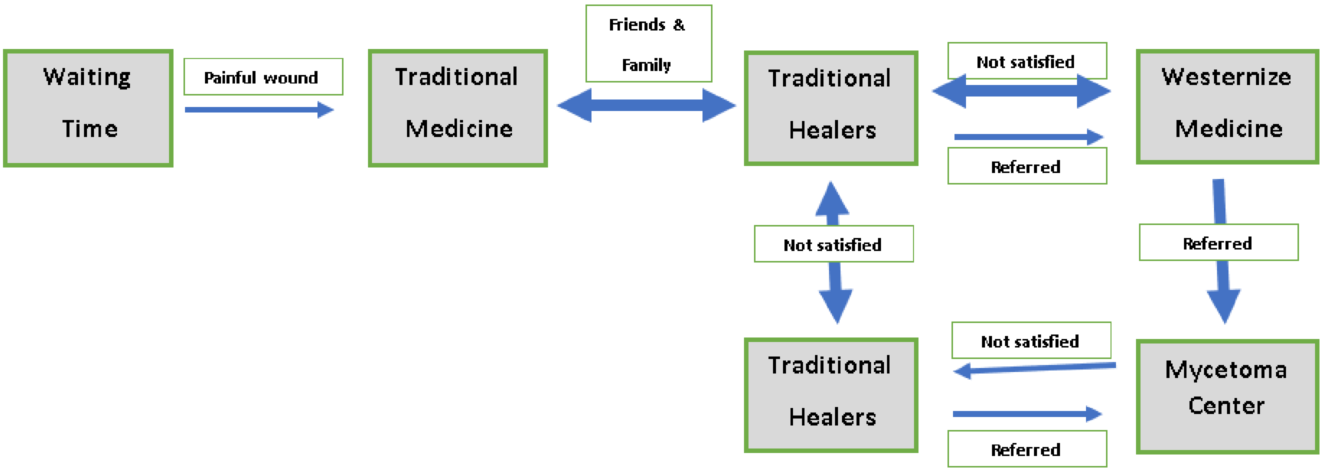

Figure 27: Health-seeking pathways for mycetoma patients in Wad Elnimear village.

Before seeking advice

Mycetoma starts with a painless lesion and thus most individuals continue their life as usual without seeking immediate healthcare. They become worried only when the lesion becomes painful and starts to interfere with and limit their daily activities.

Traditional healers are the first encounters

Traditional healers are most frequently the first healthcare encounter for those who have mycetoma in Wad Elnimear village; these healers use different modalities to treat mycetoma, either with various herbal remedies, by reciting the holy Quran *mehaya*, or prayers seeking relief from Allah (*Duaa*), or by cauterising the wound.

> Firstly, [I was] injured due to acacia thorn and after [a] long time [the] wound exuded a black matter so I went to meet the sheik.

(30-year-old male informant with mycetoma)

Most of these patients reported trying every possible treatment modality. These often included every sheikh, traditional healer, and even westernised medicine, because they were desperate and dissatisfied with the treatment outcome of each previous treatment system:

> He visited every single sheik, Abdella, Wad Alobaid, all of them. He tried every single powder and every single doctor.

(Female informant – the 45-year-old wife of a patient)

> If someone told him about [a] sheik that he can possibly treat him, he will immediately go and see that sheik.

(Female informant – the 38-year-old wife of a mycetoma patient)

> Alsheik Alsammani told him to grind *kamoon* – ‘black seed’ – mix it and apply it every morning and every night; he tried it and said it didn’t work, it only made his clothes dirty. He wanted to try it once or twice to see if it works, then he went to Soba teaching hospital, and they told him “Your hand is sprouting”.

(Female informant – the 35-year-old wife of a mycetoma patient)

> I went three times and it refused to heal; I went to Madani, Dr Magdeldeen operated on me and told me to come back after a while. It came back again aggressively with

> pain. After Madani my body became weak, my hair broke off, and I became very skinny – people did not recognise me because my hair was white, I vomited all the time. I was very distressed, then my brother decided that we should go to Khartoum.

(37-year-old male informant, personally affected by mycetoma)

One health system at a time

Some participants indicated that while being treated by a traditional healer they would never try using biomedical pills or prescriptions, nor even visit a doctor. This was because they believed that they should try only one system of health-management at a time, and this was also often the instructions of the traditional healer. A similar finding was reported by Kunna et al. (2021c).

> I tell him/her to stop taking [the] doctor’s medication for one week – I need to see if there is improvement or not, then I can advise him/her accordingly. In some diseases the medication works, in others it is not working.

(Traditional healer, male, 49 years old)

Referrals from traditional healers

While in the village, I received two patients who had been referred on by their traditional healer; he had instructed both patients to seek treatment from biomedical doctors and was following their progress by phone. These same two patients were keen to travel to the MRC in Khartoum, so I immediately referred them for further follow-up consultation.

Traditional healers also care about their own reputations and the curing of their patients, as one of the traditional healers stated:

> There are people who have infection, I do not cauterise them! Instead, I tell them to go for the doctors and do some investigation. Cauterisation is not for all cases. For some conditions cauterisation will not work – they [had] better go for doctors.

(Male informant, 49 years old, a traditional healer in Wad Elnimear village)

> Those who have mycetoma I do not cauterise them, I can differentiate it from other similar conditions like joint dislocation – they come with football injury or fall down on their foot.

(Male informant, 49 years old, a traditional healer in Wad Elnimear village)

Factors contributing to a preference for traditional healers over Western medicine when dealing with mycetoma

Multiple complex factors play interconnecting roles that affect the decisions of those who are affected by mycetoma infection. The main ones are:

The cost-effectiveness and the distance

Many patients report that the MRC is too far away to reach from their area. Each return trip to the MRC costs over 20,000 Sudanese pounds. This figure increases every day with rapid changes to transport prices, due to the instability of the currency and the general economic situation in Sudan. In addition, there are hidden costs because of the duration of the stay in Khartoum State required to fulfil each follow-up visit to the MRC. Mycetoma patients must visit the centre for follow-up treatments and consultation not once, but every six weeks; prior to each visit the patients are also required to do a liver function test. One of the patients is obliged to stay with her married sister for 10 days after each follow-up visit, during which time she cannot attend school and her education is thus adversely affected.

During interviews, one of the patients reported that visits to the centre were mainly for taking the free medication that is provided there (supported by the FMOH):

> I just visit the mycetoma research centre for the medication – it’s very expensive outside the MRC.

(Male informant, 30 years old, personally affected by mycetoma)

It is important to note that although there is one local centre for mycetoma in a nearby village, most of the individuals do not approach it, as there is no sustainable medication at this centre. Meanwhile, it is very much easier and cheaper to approach the nearest traditional healer in the region.

Although their economic situation and the long distance to the MRC were the reasons most frequently given by the participants, nevertheless, these were not the most important factors in the decision to seek a traditional healer.

Travelling time

We found that the patients of traditional healers expressed very similar perspectives to those consulting Western providers, with regard to the travel parameters necessary for their chosen treatment. Even though patients may have lived nearby to a traditional healer, they were nevertheless willing to travel long distances to reach another traditional healer.

> I heard about one of the traditional healers from my friend, in Nuba Mountain in western Sudan. I visited him seeking treatment for my foot.
>
> (Male informant, 34 years old, personally affected by mycetoma)

One of the mycetoma patients that was consulted during this study even travelled all the way to Khartoum to seek a traditional healer; the act of this individual decreases the likelihood that the seeking of a traditional healer is merely for financial reasons.

Frustration with the long duration and the outcome of treatment with Western medicine

Several patients reported their frustrations with the side effects of Western drugs and also with the long duration of their treatment, which, from their point of view, offered no significant improvement in their health.

Many patients felt dissatisfaction with the MRC, and this presented in many ways:

> They do not do anything [referring to the MRC], they do not treat the disease, and they do not amputate it.

(37-year-old male informant, whose leg was amputated in Madani hospital due to mycetoma)

> The doctor gave me the white pills. For three years I kept taking them and attending the follow-up every six weeks in vain. I got so tired with my leg. I gave them back their pills and informed them I am not going back to that doctor [after] three years of ineffective treatment. Nothing but the pills.
>
> (28-year-old male informant, personally affected by mycetoma)

> We approached the director of the MRC in his private clinic seeking his referral letter to travel to Egypt, seeking management there.
>
> (53-year-old male informant, the father of a mycetoma patient)

The value of social support

Most patients positively valued the social support they received when they spoke about their experiences in Madani hospital. One patient proudly reported:

> When I went in to operation, there were 20 of my relatives outside and 20 inside the hospital.

(30-year-old female informant, personally affected by mycetoma)

One of the patients reported that this social support is reduced when they travel to Khartoum for treatment via the MRC:

> I do not have relatives in Khartoum, I only have my brother [who] works there; I'm very grateful to his neighbour [that] they allow me to spend one week, but still, it's not like when you live in your relatives house.

(38-year-old female informant, personally affected by mycetoma)

Seeking traditional healing after Western medicine

Some of the patients even approached traditional healers after being treated through the MRC because they were not satisfied with the treatment outcomes:

> After his first surgical operation, he went to the MRC repeatedly for follow-up several times; every time they asked him to go back and come again …. He was never convinced, then he returned back to using the remedies – he carried his remedies in his bag when going to Khartoum to [the] MRC [he was using both traditional and doctor's treatment].

(38-year-old female informant, the wife of a mycetoma patient)

The perspective of healthcare providers

The doctors in the MRC blame traditional healers for their role in delaying patients' access to biomedical care and treatment pathways. The doctors view the staff working at the MRC as the proper people to treat patients with mycetoma, as the medication is given there free of charge and is supported by the FMOH. In addition, some physicians view the leading reason for patients' not seeking treatment within the MRC as being due to their economic situation:

> Most of the mycetoma patients arrive at the centre very late; they take much time with traditional healers and taking home remedies. This delay may raise the possibility of having surgical intervention and maybe even amputation.

(Doctor working in the MRC)

> If they have money, they will immediately come to the centre, they will never approach the traditional healers.

(Doctor working in the MRC)

فوجدنا منزله يعج بالناس و صراخ الاطفال، فدخلني رعب لم أنساه
قط حين جاء دوري، حاولت الهرب فلم أستطع ...
فقام البصير بكي باطن قدمي فتألمت ألما فظيعا وتمنيت أن تكون
هذه نهاية الورم. في تلك اليلة لم أنم من شدت الألم، و لم أستطع
ان أطأ على قدمي لمدة ١٠ أيام. لم يختفي الورم وما زالت قدمي
تؤلمني، و بدأ يخرج منها صديد و حبوب سوداء كما إني أصبت
بالحمى ....

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Figure 28: Picture illustrating a boy being taken by his family to one of the traditional healers.

Figure 28 (above) is a picture of a vignette that is displayed in the MRC waiting area. The vignette tells the story of a little boy taken to visit a traditional healer. The text, written in Arabic says:

> We [referring to the boy and his family] found his [referring to the traditional healer] house full of people and the sounds of crying boys. I severely panicked

when it was my turn – I will never forget that fear ever in my life – and I tried to escape but I couldn’t do so.

Then the traditional healer cauterised the sole of my foot; I felt very bad pain, and wished for the end of this swelling. I didn’t sleep that night, and I couldn’t walk on it for 10 days. The swelling did not go away, and my foot was still painful. In addition, there were pus and black grains coming out from the wound and I also had a fever.

وفي فترات إنقطاعي عن العلاج كنت أستعمل العلاجات البلدية
التي يُصفها لنا أهل المنطقة، من عسل، كمون أسود، حلبة،
ودك الضان، وخلطات من بعض المشائخ، و لكن بدون جدوى.
فعدت من جديد إلي المركز وإنتظمت في العلاج وتحسنت
حالتي كثيرا، وأخذ الورم يتلاشى تدريجياً وواصلت دراستي
بالجامعة. وبعد مرور ستة أشهر من العلاج المتواصل تم بحمد
الله شفائى تماما، كما واصلت الحضور للمركز بدون إنقطاع
كل ستة أشهر، للمتابعة الدورية والتأكد من عدم رجوع
مرض المايستوما.

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Figure 29: Illustration taken from the MRC waiting area – a young man visiting the MRC doctor.

Figure 29 illustrates a vignette of a young man who had previously used alternative traditional remedies such as honey, dried lime, fenugreek seeds, and others prescribed by traditional healers and sheikhs. The young man states that none of these remedies worked with mycetoma, but that when he returned to the MRC after visiting the traditional healer, his disease was completely cured after six months of continuous management at the MRC. As is stated below the illustration, the young man was also able to commence studying at university once the swelling had gone, and he was only attending for a follow-up visit every six months to make sure the disease did not return.

The illustrations in figures 28 and 29 reflect to some extent the views of the MRC towards the traditional healer; the images inside the centre convey the idea of the traditional healer as a sad, ugly, and non-smiling person while the doctors in the MRC are depicted as being smiling and welcoming. Furthermore, Figure 28 portrays the negative emotions of suffering, pain such that there is no sleep, and the notion of needing to escape from the traditional healers, while Figure 29 presents the patient who visits the MRC with positive emotion, full of smiles, and expressing regret only for having visited the traditional healers and taking their remedies.

In addition, the posters communicate the idea that disease remission and reoccurrence happens only when dealing with traditional healers and their remedies, while in contrast, a cure is possible with only six months of continuous treatment and follow-up at the MRC. This is conveyed by presenting a diseased foot with great emphasis on the mycetoma wound with the patient visiting the traditional healers, while in the other illustration a fully cured foot is shown, without any sign of the disease, or of any consequences such as an amputation, or any complication such as a surgical scar.

It is also crucially important to recognise the difference between how the traditional healers are drawn compared with the portrayal of the healthcare professional: the doctor is given a smiling face and features and a slightly lighter skin colour; in contrast, the traditional healers are given a more Arabian look with darker skin tones, Arab-style moustaches, and a meaner overall look. This may indicate an underlying assumption that the more ‘Western’-looking doctors are more trustworthy than the Arab-appearing traditional healers. However, it is also likely that the intention behind these simple portraits is the underlying respect for foreigners as compared with locals.

Another observation that has been made in the context of the MRC is the potential impact of the attire worn by doctors on the patient experience. The traditional ‘formal white coat’ worn by doctors can sometimes create a perception of authority and power that may further widen the gap between doctors and mycetoma patients. While some studies recommend the wearing of the white coat to create an image of authority, attractiveness, and trust (Gary, 2004), in the context of the MRC, wearing the white coat may facilitate a power dynamic between the physician and patient, potentially counteracting and antagonising the role of traditional healers and contributing to negative perceptions of their practices.

This dynamic can be understood as part of the larger history of marginalisation and devaluation of traditional healing practices by Western biomedical models of medicine. The white coat, as a symbol of Western biomedical authority, can serve to reinforce this dynamic and exacerbate the gap between Western biomedical practitioners and traditional healers.

To address this issue, it may be important to consider alternative approaches to the physician–patient relationship that prioritise collaboration and mutual respect. This may involve rethinking the attire worn by doctors, as well as adopting more inclusive and culturally sensitive practices that acknowledge and value the role of traditional healing practices in the context of mycetoma treatment. By working to bridge the gap between Western biomedical practices and traditional healing practices, we may be able to improve the patient experience and outcomes for those affected by mycetoma.

The illustrations in figures 28 and 29 illustrate how the MRC not only stigmatises traditional healers and views them as a fundamental cause for delay in the management of mycetoma disease, but may also even act against them in that the MRC antagonises the traditional healthcare system.

Discussion

This chapter has explored the existing pathways for the management of mycetoma disease. Traditional healers play a major role in the journey of mycetoma patients, with most individuals seeking care from them either before or alongside biomedical health facilities. Patients' decisions to seek care from both traditional healers and biomedical health facilities were associated with different factors, among which were dissatisfaction regarding the outcome of specific treatment modalities and the need for social support. I have identified different pathways for mycetoma management, with some patients seeking care exclusively from traditional healers and others seeking help from both traditional and biomedical health facilities.

The findings of this chapter highlight the importance of recognising and incorporating traditional healing practices into the management of mycetoma. It is crucial to understand the reasons behind patients' decisions to seek care from both traditional and biomedical health facilities, as well as the impact of these decisions on treatment outcomes. By acknowledging and respecting traditional healing practices, healthcare providers can work towards improving patient satisfaction and ultimately achieving better health outcomes for individuals living with mycetoma.

In this chapter I have described the findings and results of previously published studies carried out by the MRC, which presented traditional healers as major contributors to the delay in patients' seeking biomedical treatment through the MRC (Elkheir et al., 2020a; Ezaldeen et al., 2013b; Fahal et al., 2014; Kunna et al., 2021a).

Previous studies on the role of traditional healers in treating mycetoma disease have been criticised for focusing solely on patients receiving treatment at the MRC; although the patients had given their consent, their responses may have been influenced by the fact that they were receiving free medication from the centre. This limited focus also fails to capture the true behaviours of patients seeking treatment for mycetoma in natural settings, where traditional healers often play a significant role. The westernised system employed by the MRC is not representative of the full range of medical treatment options available for mycetoma patients.

Several studies have examined why some people afflicted by illness consult a doctor while others with the same complaint go to traditional healers (Helman, 2007; Zola, 1973). Helman suggests that this is often the case either because people cannot afford to pay for medical care or because it is not available to them. However, even when they can afford it, there is often little correlation between the severity of a physical illness and the decision to seek medical help. In some cases, this delay can have severe consequences for the person's health. In this study, we have shed light on the importance of the social support that mycetoma patients receive during their journey; lack of this social support may present as a major obstacle in their obtaining biomedical treatment, in addition to the varied economic reasons. Moreover, this is supported by additional hypotheses, which also state that social relationships influence individuals' health and wellbeing under all conditions, as is stated by Loucks et al. (2006). Furthermore, buffering hypotheses suggest that social relations are predominantly influential during times of stress (Uchino, 2006).

In this study I have used the concepts of simultaneous and sequential healthcare-seeking pathways as I found that some of the patients only employed one health system or treatment modality at a time, and this behaviour is strongly supported by the evidence provided by traditional healers themselves. Kunna et al. have reported on this, but the magnitude of this phenomenon is more remarkable than their reports have ascertained, as only four of the patients from their study data were asked to abandon their allopathic medication by traditional healers

(Kunna et al. 2021c). The involvement of two systems at one time was also reported in our study. Several factors appeared to justify this action, as mycetoma patients were doing whatever they could to treat the disease, especially as there is neither a definitive treatment for mycetoma nor a definitive diagnostic modality (Ahmed et al., 2017; Emmanuel et al., 2018a). In addition, the chronicity of the disease and the lengthy duration of the biomedical treatment pathways both play additional roles in the medication's side effects and the high rate of recurrence.

Some researchers and policymakers have argued that in Africa it is mainly the poor, marginalised, and less-educated people who seek care from traditional healers, and that they do so because these healers offer treatment at lower cost and are easier to reach (Labhardt et al., 2010). This assumption is also held by many of the healthcare providers of biomedical mycetoma treatment. This study challenges these assumptions by showing that there are additional factors contributing to these treatment choices. Furthermore, some of the individuals affected by the disease travel long distances to seek traditional healers' opinions. In research that supports our results regarding patient choice, studies in Cameroon on the treatment of epilepsy have shown that patients deliberately choose traditional care, even though it is 20 times more expensive than Western medical treatment (Njamnshi et al., 2009; Preux et al., 2000).

Another factor is that traditional healers interact differently with their patients compared with healthcare providers who have been trained in Western medicine. Traditional healers are significantly more patient-centred in several respects, key examples being that they focus more on psychosocial topics and daily life issues than on purely medical questions; they also more often ask for their patient's opinion, and frequently discuss their concept of illness (Labhardt et al., 2010).

The power dynamics between the two health systems in the management of mycetoma

This study is the first to identify the health-seeking pathways for mycetoma disease in Sudan, and how these pathways can cross over between the two existing systems relating to mycetoma. The power dynamic between biomedical Western medicine and traditional healing practices regarding mycetoma in Sudan is complex and multifaceted. It plays a vital role in the patients' choosing between the two systems, and this is especially true for marginalised communities who may feel excluded or mistreated in Western healthcare systems. Patients who feel disempowered may be more likely to seek alternative healing practices.

Traditional healing practices have been marginalised and devalued by biomedical Western medicine in the form of the MRC. This marginalisation has often been driven by a number of factors, including the colonisation of many parts of these institutions by Western powers, the influence of Western pharmaceutical companies, and the dominance of biomedical Western medical practices within health institutions.

The predominance of biomedical Western medicine in the treatment of NTDs in Africa has had many effects. Western medicine has made considerable strides, as seen, for example, in the creation of potent medication therapies for conditions such as malaria and schistosomiasis (Tariq et al., 2019) and the first mycetoma randomised control study (Van de Sande et al., 2018). Western biological medicine's pre-eminence has, however, also had a number of detrimental effects. First, the marginalisation of conventional medical procedures: mycetoma's traditional healing methods are based on regional wisdom and methods that have been handed down through the generations in the area. This marginalisation has also resulted in the disregarding of local knowledge and practices that have been crucial to the health and wellbeing of particular communities in Sudan. These techniques are frequently culturally specific and take into account village beliefs and values. Moreover, the MRC's focus on biomedical Western medicine has resulted in a disregard for other elements that can aid in controlling the spread of mycetoma, such as sociocultural and economic issues. In addition, patients who visit the MRC for westernised medicine often lament the lack of certain essentials, such as social support, which drives them to seek management from traditional healers.

Furthermore, the dominance of the MRC's approach, which is based mostly on biomedical Western practices, has negatively impacted the doctor–patient relationship in the context of mycetoma management. This approach, which can be seen as an expression of the dominance of Western biomedical medicine, may not align with the cultural beliefs and practices of the people in Wad Elnimear village, who have a preference for traditional healers. Despite their discomfort with Western biomedical practices, the villagers may feel compelled to accept treatment from the MRC due to the perceived authority and power of Western medicine and its institutions.

The dominance of Western biomedical practices in the MRC can also be seen in the attire worn by the doctors, which includes the traditional white coat that is associated with Western medical professionals. This attire may further reinforce the power dynamic between the doctors and patients, and may contribute to a breakdown in communication and trust. Such domination can also be seen not only in the fact that free medication for mycetoma is given only under the umbrella of the centre, but also in the MRC’s connections with Western institutions (which have been mentioned in previous chapters). This breakdown in communication and trust may be further exacerbated by the fact that the MRC is a westernised institution that may not fully understand or respect the cultural beliefs and practices of the local community.

This chapter has also illustrated the role of traditional healers in mycetoma treatment in Sudan by showing that traditional healers are a disease-management and treatment option for rural and peri-urban populations.

These findings may encourage policymakers, programme managers, and healthcare providers for the public health system to allow patient-centred communication to become an integral part of their services, and to facilitate better understanding of the power dynamic between the existing systems for health and illness in the management of mycetoma and other NTDs in Sudan and Africa; this would improve both the quality of care and patients’ perceptions of such care, and subsequently enhance the effectiveness of public healthcare programmes utilised for the prevention and management of mycetoma.

The MRC not only stigmatises traditional healers but also actively works against their medical system. The negative portrayal of traditional healers is evident in the images found displayed inside the centre, in which the healers are depicted as sad, ugly, and non-smiling people; in contrast, the doctors in the MRC are shown as welcoming, friendly, and smiling. This can create a perception among patients that the traditional healers are less trustworthy and are inferior to the biomedical doctors.

Moreover, the illustrations also imply that seeking treatment from traditional healers can result in further suffering and delay in the management of the disease. The MRC, by contrast, is presented as the only place where the disease can be cured effectively, and the only way to achieve complete remission of the disease. This portrayal is supported by the testimony of a patient, who claims that after six months of continuous treatment and follow-up at the centre, his disease was completely cured, and he was able to continue his studies at university.

The negative portrayal of traditional healers in the MRC can be seen as a form of cultural imperialism, wherein Western biomedical practices are promoted as superior to traditional medical practices. This could result in the loss of traditional knowledge and the devaluation of indigenous medical practices, which could have negative implications overall for the health and wellbeing of local communities. Furthermore, the difference in how doctors and traditional healers are depicted in the illustrations, with doctors having a lighter skin tone and a more Western-looking appearance, may also reflect an underlying assumption that foreign doctors are more trustworthy than are local traditional healers.

In conclusion, the role of traditional healers in the management of mycetoma disease in Sudan cannot be underestimated. The dominance of biomedical Western medicine has often led to the marginalisation and stigmatisation of traditional healing practices. This, in turn, has negatively impacted doctor–patient relationships, as patients may feel uncomfortable with Western biomedical practices and desire treatments that align with their cultural beliefs and practices. While Western biomedical treatments may be effective in some cases, it is crucial to recognise the importance of traditional healing practices and the need to integrate them into the healthcare system. This can be achieved through building trust and collaboration between traditional healers and Western medical professionals, as well as by creating a more inclusive and culturally sensitive healthcare system. If this is done, patients will be able to receive the best possible care that aligns with their cultural beliefs and practices, leading to improved health outcomes and overall satisfaction with the healthcare system.

In Chapter Seven, I move to an exploration of mycetoma and its management at the micro level. I highlight the lived experience of mycetoma patients in Wad Elnimear village in a natural setting, and the different types of stigma encountered by these patients, their caregivers, and even the village.

Chapter Seven

Concealed Narratives – Stigma as Experienced by Individuals with Mycetoma

Chapter Seven: Concealed Narratives – Stigma as Experienced by Individuals with Mycetoma

Introduction

The previous chapters of this thesis have shown that Sudan is an economically and governmentally fragile country, with a struggling health system. I have also shown throughout the thesis how these contextual factors have not only created fertile ground for the unchecked spread of mycetoma, but have also limited disease control efforts both locally and nationally through the use of methods that did not involve the local communities. This is also influenced by a national predilection for using top-down approaches to disease control and for centralising the response to the disease, which is in turn attributable to an underfunded and underpowered mycetoma response, and also to significant power imbalances across the MRC, FMOH, and SMOH, which are the organisations that currently lead mycetoma research and control in Sudan. This structural negligence has translated into a failure to prevent or respond to the endemicity of mycetoma in Sudan (Sergi & South, 2016). Throughout this chapter, I further engage with the power imbalances of the current interventions by illustrating how these *top-down disease responses* (Parker & Allen, 2014) have been internalised within Sudanese society and the perceptions of Sudanese communities, groups, and individuals. Mycetoma is not only an NTD, it is a disease that comes with consequential deformities, and an intrinsic lack of anonymity. As Abbas et al. observed, the disability is not only physical, but social too (Abbas et al., 2018), which prompts questions on societal perceptions of the illness and the stigma that has been built around mycetoma.

Throughout this chapter, I dive into the individualised experiences of the disease. Often, public health responses are too broad and large in scale to consider ‘lived experiences’, so in this chapter I hope to complement the currently ‘recorded’ knowledge with a deep interrogation of the day-to-day experiences of people affected with mycetoma. This bridges a gap between the previous chapters – on high-level (‘macro’) players in mycetoma – and the next level (‘meso’), which focuses on community-level responses and reactive support systems. This section builds on the understanding of lived experiences by assessing the case study of a young man, who, for the purposes of this dissertation, is named Ahmed. I began this thesis with my interaction with Ahmed; now, an analysis of Ahmed’s condition, his livelihood, and subsequent societal adaptations is highlighted in this chapter using an anthropological lens. The chapter then considers the wider societal implications and the social fabric around the illness – narrowing down on stigma and its implications, before defining its possible linkages with broader discrimination – and finally grounding the evidence in a discussion of how this is relevant to mycetoma responses in Sudan.

How stigma is born: theories and conceptual models

Stigma is defined in different ways by different people. Link and Phelan (2006), for instance, defined it as a social process that exists when elements of labelling, stereotyping, separation, status loss, and discrimination occur within a power situation that allows this structural determination. In turn, Weiss, Ramakrishna, and Somma (2006) defined it as a social process, or related personal experience, that is characterised by exclusion, rejection, blame, or devaluation and that results from the experience or reasonable anticipation of an adverse social judgement regarding a person and/or a group. In health-related stigma, this judgement is based on an enduring feature of identity that is conferred by a health problem or a health-related condition. However, the definitions of these concepts and theories have evolved over the past six decades since the Canadian sociologist Erving Goffman first explained the idea (Bastable et al., 2008). As a result, discussions around stigma often involve sociological and psychological dimensions that describe the dynamics and the process of stigma, that is, how the political and social aspects are related, how stigma is then produced, and the way in which it subsequently reproduces social inequities (Tyler & Slater, 2018).

Stigma can be sub-divided into the ‘perceived’ (internalised or felt) and the ‘enacted’ (Frank et al., 2018). Arguably, perceived stigma refers to the devaluation, shame, secrecy, and withdrawal that is triggered by applying negative stereotypes to oneself (Corngan, 1998); by contrast, enacted stigma can be understood as referring to the actual experience of the discrimination, and/or the individual’s embarrassment and shame that is associated with their condition (Frank et al., 2018). Discrimination is an unjustifiable and unfair ‘different treatment’ that is directed towards people and/or groups that are perceived as being ‘different’ (Turner & Ross, 2006). Any measure that entails a distinction among persons may depend on their confirmed or suspected health status (Caraël et al., 2000)**.**

Stereotyping is the belief that *all* members of a group possess the same characteristics or traits that are exhibited by *some* group members (Van Brakel, 2006). While acknowledging the role of interpersonal process as being involved in stigma, psychologists (Hoelter, 1983; Smelser, 1999; Verkuyten, 1994) have also studied the internal behavioural processes that can lead to *self*-stigma when people then internalise these public attitudes, and suffer numerous negative consequences as a result. Many individuals have been observed to experience stigmatisation associated with their illness to the extent of social isolation (Wigens, 2010).

Stigma and chronic conditions: the straw that breaks the camel's back

Stigma has been observed to occur in many chronic health conditions, including leprosy, HIV/AIDS, mental illness, epilepsy, disability, and tuberculosis (Jacoby et al., 2004; Kaur & Van Brakel, 2002; Nyblade et al., 2003). In addition, stigma and its psychosocial consequences can cause indescribable suffering to those who are stigmatised. As Link and Phelan (2006) state, stigma can be considered to be the result of a process in which a series of five interrelated components combine to then generate stigma. First, people must distinguish and label a particular human difference as socially salient, resulting in culturally derived categories that are used to differentiate people into groups. Second, labelled differences must be linked to a set of undesirable characteristics thus forming a negative cultural stereotype (or oversimplified characterisation) that is summarily applied to every member of the group. Third, those who are so labelled and stereotyped are seen as fundamentally different from the dominant group, creating an 'us–them' demarcation. Fourth, stigmatised groups are socially devalued and systematically disadvantaged with respect to access to social and economic goods (such as income, education, and housing status), creating poorer health and social outcomes. Discrimination may be experienced in the context of individual interactions, or it may be structural, when accumulated institutional practices create inequities. Finally, stigmatisation is entirely contingent upon access to social and economic power, as only powerful groups can fully disapprove of and marginalise others (Stuart, 2001).

Labelling human differences: are people tagged for life?

Link (Link & Phelan, 2006) has also argued that although most human differences are socially irrelevant, differences such as skin colour, intelligence quotient (IQ), and sexual preferences, are all highly salient in many social contexts. The point he is making is that there is a social selection process that determines which differences are deemed relevant and consequential, and which are not. For example, medical conditions vary dramatically in the extent to which they are socially significant. Compare, for example, the varying levels of stigma associated with hypertension, bone fractures, melanoma, incontinence, AIDS, and schizophrenia.

The process of stereotyping starts with a person being ‘labelled’; next, the label is linked to certain undesirable characteristics. During the third processual component, there is the appearance of ‘labelling groups’, which separate the stigmatised person(s) from the stigmatiser**(s).** The fourth component involves stigmatised people’s then experiencing unfair treatment, discrimination, and a loss of status. We can reason that when people are labelled, set apart, and linked to undesirable characteristics, a rationale is constructed for devaluing, rejecting, and excluding them. Finally, the fifth component of stigma is the exercise of power by the stigmatiser over the stigmatised.

The role of power is clear, for instance, in situations where low-power groups attempt to reverse stigmatisation. For example, patients being treated for mental illness may label their clinicians as ‘pill pushers’ – a cold, paternalistic, and arrogant ‘them’ to be despised and avoided (Link & Phelan, 2014). Regardless of their experiences and potential experiential insights, these patients lack the social, cultural, economic, and political power to inform interventions affecting them, and to translate their experiential knowledge into the treatment received. The staff, in such circumstances, hardly constitute a stigmatised group.

The double-edged sword of stigma and discrimination

The two concepts of stigma and discrimination are often seen together. These, however, cannot be used interchangeably, as they do not have the same meaning. While stigma refers to a person being seen in a negative way, discrimination refers to a person being treated in a negative way (Togioka et al., 2023). The term ‘discrimination’ encompasses three major forms of discrimination, which can, in turn, entail varying degrees of severity. Direct discrimination occurs, for example, when a mycetoma patient receives an overt rejection of a job application because of their disease, or the refusal to rent an apartment, and so on. Structural discrimination is more subtle. A salient example would be a mycetoma patient who relies on job recommendations from their colleagues, but these colleagues are more likely to recommend disease-free candidates. Similarly, there may be no direct denial of a job to a person of colour, yet discrimination has occurred. Another example of structural discrimination is evident when treatment facilities for stigmatised diseases like schizophrenia are isolated, or are located in poor or dangerous neighbourhoods. Finally, an insidious form of discrimination occurs when stigmatised individuals realise that a negative label has been applied to them and that other people are likely to view them as therefore being less trustworthy, less intelligent, and more dangerous and incompetent (Link & Phelan, 2006).

Neglected and *then* stigmatised, or neglected *because* of stigmatisation?

Several studies have concluded that high levels of stigma are associated with NTDs (see, for instance, Engelman & Steer, 2018; Hofstraat & Van Brakel, 2015a; Prochazka, et al., 2020). For example, a study examining the stigma that is associated with lymphatic filariasis in the Dominican Republic concluded that social disconnectedness appears to exacerbate the negative consequences of living with lymphedema among women (Person et al., 2007). Social connectedness and cultural scripts often define a social role for women that transcends physical deformity and disability. In contrast, disrupted social connectedness contributes to social isolation, depressive symptoms, and poor health outcomes. In other words, the stigma that is perpetuated by physical appearance in the case of these women then changes the social role that these women play, and they begin to feel a burden to their family. Another study that examined the stigma around schistosomiasis in Kenya highlighted that individuals who are infected with schistosomiasis are then stigmatised; this is because they are considered premortal or promiscuous if they are females (Person et al., 2007). Skin diseases are often medically overlooked (Wu & Cohen, 2019); however, the perceived stigma of skin diseases affects job opportunities, social activities, marriage, relationships, and self-image. Furthermore, the location of skin lesions – which then determines their visibility – is also strongly associated with stigma, that is to say, if the skin lesion can be covered with cloth (on the thighs or elbows, for example), it generates less felt stigma in comparison with more clearly visible skin lesions (such as those on the face or neck) (see Roosta et al., 2010). While this was found to be the case with acne and eczema in a previous study, reactions to other skin diseases can – and have – escalated from stigma to discrimination; taking the case of albinism, for example, patients report being threatened by their partners, they are more likely to drop out of school, and they are unable to compete in the job market (Brocco, 2016).

Scabies is one of the cutaneous NTDs that are associated with stigma (Engelman & Steer, 2018). The felt stigma in scabies patients is often avoided by concealment of the visible signs of the disease, on the assumption that people would deliberately dissociate from the patient if the symptoms were visible (Trettin et al., 2018). Patients must balance between the obligation to inform people – thus reducing contagion – and, on the other hand, preferring not to let people know about their illness. In some cases, patients described informing others about their diagnosis, and how this created feelings such as hurt, anguish, and shame when subsequent rejection occurred (Trettin et al., 2018); in these instances, scabies remained a barrier to creating and sustaining social connectedness, leading to an increased sense of loneliness and isolation. Although in Lopes' (2019) study, the symptoms of the disease had implications for work productivity and school absenteeism, it was also reported that infection contributed to social isolation and inhibition, especially among children, who changed their behaviour and social interaction in response to their illness. A low economic state can also be a cause *and* a consequence of scabies (Lopes et al., 2019).

The underlying reason for stigmatisation is often the belief that the disease in question is either genetically susceptible or infectious, thereby resulting in a fear of contagion. However, physical appearance, the inability to fulfil a certain societal or gender role, being a burden to the family, and witchcraft or a curse from God, have also been identified as reasons for stigmatisation (Hofstraat & Van Brakel, 2015c). Unlike in the case of podoconiosis, factors such as age, gender, and level of education may not usually impact the level of stigma, according to the majority of completed studies and syntheses of data that have been gathered within this area of NTD research, as, for example, Deribe et al. have claimed (2013b). In the case of podoconiosis stigma in Ethiopia, manifestations of enacted stigma may include: spitting on patients, exclusion, avoidance, derogatory name-calling, generalised 'looking down' on podoconiosis patients and their families, and intra-partner violence (Deribe et al., 2013b). In addition, anticipated stigma is often reported, with there being a fear of insults or mistreatment, and an associated fear of disclosure, manifesting in the tendency of patients to hide themselves and their condition. Internalised stigma can emerge in feelings of shame or guilt, living in fear, suicide attempts, and patients' perception that stigmatisation is normal. The complex consequences related to the stigmatisation of podoconiosis are therefore social, psychological, and health-related in nature.

Stigma is a hidden symptom of mycetoma – seen by none, but felt by all

Van de Sande (2017) has argued that mycetoma shares characteristics with most NTDs, and also considers mycetoma patients to be stigmatised (Van de Sande et al., 2017). A study conducted in the Sudanese MRC also considered mycetoma to be a source of social stigma (Bakhiet et al., 2018), which was particularly common among females and children. According to the authors, because of the stigma, the women and children hid their disease for a more prolonged period, until they were compelled to seek medical care. This is often the reason why the condition is presented at a later stage of development and, hence, the reason for there being a greater number of cases of a more progressive disease, then requiring surgical involvement, which consequently leads to lifelong disabilities and places further burden and stigma on those individuals who are diagnosed with the disease and their families. This has severe socio-economic consequences, including a high rate of school ‘drop-outs’ for children, and negative impacts on the marital status and employment of young adults (Fahal, 2004). Research indicates that individuals who are diagnosed with mycetoma are negatively affected psychologically because of the lack of available health services, their physical disability, and the lack of prospects, as the outcome of their treatment is weak or ineffective and often leads to amputation of the affected part of the body (see Fahal, 2004; Zijlstra et al. 2016).

A recent study addressing the stigma in mycetoma was aimed at determining the disability associated with mycetoma in the MRC (Abbas et al., 2018).The authors suggest that women may be less likely to seek or receive medical care due to stigma, financial, or ‘gender-role’ considerations, leading to reporting bias. Females may have similar risks of exposure as men due to their involvement in extensive outdoor activities such as collecting wood for cooking. The MRC supported this explanation in a village-level survey, which showed that gender and age distributions were more evenly distributed than were those measured at the tertiary level, such as the MRC (Fahal et al., 2014). Fahal et al. also claimed that stigma and social isolation are the main cause of the reduced participation of mycetoma patients in education, and in community, religious, social, and civic life, and recommended further study of this aspect of stigma. This chapter responds to this gap in knowledge.

Even though Sudan reports the highest number of cases globally, the prevalence of mycetoma is unknown, and the management is not uniform (Sampaio et al., 2017; Van de Sande et al., 2017; Zijlstra et al., 2016).There is no preventive or control programme, and no early-case recognition or surveillance system for mycetoma disease (Hay & Fahal, 2014). Moreover, knowledge regarding sociocultural understanding is limited to case reports and passive case detection (Bakhiet et al., 2018). Therefore, although study of the area of stigma has been recommended, there have been no studies on mycetoma disease addressing the sociocultural aspect of the disease in a qualitative way. All instances of stigma are linked to disabled mycetoma patients, so the question of whether this stigma arises from the disability or from the illness itself has not been examined, and the issue calls for more in-depth qualitative data rather than simply quantitative data. In the next section, I shed light on mycetoma-related stigma as one of the prominent themes from my fieldwork.

Stigma and mycetoma in Wad Elnimear village

Through Ahmed's story, I gained valuable insights into the complex and multi-dimensional nature of the stigma surrounding mycetoma. His experiences serve as a powerful reminder of the urgent need to address stigmatisation and to foster my understanding of the issue. In the following sections, I explore the various dimensions of mycetoma-related stigma, and the underlying power dynamics that sustain it, aiming to pave the way for more effective strategies to combat stigma and support those battling this neglected disease.

Both types of stigma – felt or perceived and enacted – were found in the study site in relation to mycetoma. Most of the patients encountered felt stigma, as well as enacted stigma; some community members relate the disease to genetic causes, with the ability to be transmitted through families:

> There are only five families here who suffered from the disease.
>
> (45-year-old male informant, community member in Wad Elnimear village)

When I traced back the families referred to in the quote above, it became clear that they were not the only families who had encountered the disease; however, they were all families who had more than one relative with amputation due to mycetoma disease.

Felt stigma was also reported on several occasions both by individuals with mycetoma and by caregivers, and it varied with the disease stage. For example, there is more avoidance behaviour on the part of the person affected by mycetoma when the disease starts actively producing grains. On several occasions, enacted stigma was observed from the caregiver and the community towards the individual with mycetoma, more precisely for the wound, pus, and the odour.

> It started producing pus; there were six sinuses that produced a lot of pus. He goes to the hospital to clean it; the doctor was fed up and said Adel [her husband] should stay at home; he got gloves and antiseptic to clean it at home …. His hand used to discharge a lot of *kamoon* – black grains – and blood, and it smelled very bad; it was 'the odour' that hurt and affected all of us – if we missed one day without cleaning it, it started to smell. He was embarrassed by his hand to the point he didn't go to meet the men outside; he said: "look at how my hand is pouring *kamoon*, and there are flies on me".

(34-year-old female informant, the wife and caregiver of a mycetoma patient)

The pus and wounds are not a one-day event in the journey of the disease; they can continue for several months and years due to the chronicity of the disease:

> We got gauze and cotton so he could clean the wound at home; it produced a lot of *kamoon* – ‘black grains’ – pus, and blood. This continued for a long time – four years – it annoyed him so much …. He stayed at home and wasn’t able to do anything. He slept and woke up, and his clothes were wet with pus; they told him to cover it with gauze, he did, and his skin peeled from the heat and the gauze.

(41-year-old female informant, caregiver)

This stigma carries a very disabling effect: even before reaching the point of amputation, the patient will be prevented from going outside and practising their social life just because of the odour and the wound. Men and women with mycetoma are often discriminated against, and isolate themselves from others because of the fear of stigmatisation. One of the essential findings is that the stigma from the wound and odour of the disease will decrease from the point at which the individual with the illness can resume a significant part of his or her social life and return to work; this is evidenced by one of the caregiver’s witnessing the return of her husband to work after the disappearance of the wound. However, I cannot assume the complete disappearance of the stigma when the wound and odour no longer exist.

> He fears people will hate him because his hand discharges *kamoon* and smells very bad; on top of this, the flies are going to come around his hand. He doesn’t go to social events, as some people avoid him [for] fear of getting the disease, and even if he does, he doesn’t stay for a long time. But after he recovered, he went to work as usual.

(30-year-old female informant, the wife of a mycetoma patient)

> What annoyed me the most was the pus and the *kamoon* and his pain, but when we clean it with antiseptic and saline, he feels better; before that he would be very irritated.

(35-year-old female informant, the caregiver of a mycetoma patient)

The stigma may lead to various consequences; one of the individuals who was affected by the disease and had an amputation tried several times to get jobs, but was unable to find work, except with his uncle:

> Now I work at my uncle’s shop; no one accepts me to work with them.

(37-year-old male informant, personally affected by mycetoma)

The struggle for acceptance is not only about work but also relates to various social events, religion, and marriage, especially for those who have had an amputation, as several respondents pointed out:

> The children would pass me by on their way to school, and I would be laying on *al-angareeb* [a traditional bed]. In social gatherings, I can’t get to the location walking, now that my leg is amputated; if you don’t have a car, people will go to the social gathering and leave you.

(37-year-old male informant, personally affected by mycetoma)

Having an amputation because of mycetoma may also cause fear of hatred and rejection, anger, disappointment, irritation, and frustration and cause more isolation. It can extend to feelings of embarrassment and to not participating in religious and social interactions like weddings and funerals:

> I am not embarrassed by my leg, it’s God’s will, but when I ask a woman’s hand in marriage, she refuses because I have one leg; no one says that to my face, but they say it to my uncle, I also hear women whispering it.

(37-year-old male informant, personally affected by mycetoma)

> I was in third grade when I left school; I couldn’t walk around then; I had to stay lying in bed. I couldn’t even sit straight. Hajo, my brother, did not get a *madura* [the local name for mycetoma]; he just got a small mycetoma lesion. So, he takes me to the bathroom, puts me in the chair. He is the one who brings money to our whole family.

(37-year-old male informant, personally affected by mycetoma)

In the case of a local woman who experienced mycetoma infection leading to subsequent surgical intervention and amputation, she divorced her husband a few months after the start of the disease. However, she denied any association of the disease with her divorce; she stated that she has now been divorced for over ten years, rejecting all men who approach her. She currently lives without any job and lacking the full capability to practice her daily activities in her home:

> When this started – the disease – I felt I put more burden on my brothers; they are all married with their wives and children …. I stayed in this house, and I don't work … but my brother keeps caring for me ... several men approached me for marriage, but I don't want to; why I should have another headache, the disease and a new husband?

(32-year-old female informant, personally affected by the disease)

Although amputation can become a barrier to a female's getting married, if the disease were managed in its early stages, the stigma might be reduced and hence be less of a burden to the marital life of the female; several other females with mycetoma have been known to get married after being diagnosed with the disease. However, even when mycetoma is a very superficial wound, before it reaches the amputation stage, it can also affect other aspects of life. I also learned about the physical limitations Ahmed encountered and the emotional toll it took on him; he told me one day:

> Sexual intercourse is a challenge for me with one leg; she helps me when she feels I am struggling. It annoys me when I can't help myself.

(Ahmed, 35 years old, diagnosed with mycetoma)

These insights prompted me to explore the psychological and emotional support systems available to mycetoma patients and their families. It became evident that holistic care must encompass not only physical wellbeing but also mental health and psychosocial support.

Structural stigma: examining mycetoma stigmatisation beyond the individual at the village level

During my ethnographic fieldwork, I had the opportunity to engage with people living in some of the villages surrounding Wad Elnimear, which had gained a reputation for having the highest prevalence of mycetoma disease in the region. The villagers themselves, as well as individuals from neighbouring areas, often made reference to Wad Elnimear as a focus of mycetoma cases.

This perception seemed to have taken root due to various factors, including the concentrated efforts and frequent presence of staff from the MRC, the SMOH, and from NGOs that were trying to control the disease specifically in Wad Elnimear village.

The magnitude of the attention from national and international actors towards Wad Elnimear and Wad Onsa was undeniable. The MRC had established a strong presence there, conducting extensive studies, implementing health interventions, and offering specialised care for affected individuals. The SMOH, recognising the urgency of the situation, had also invested significant resources to combatting mycetoma at this particular location. Furthermore, NGOs played a vital role by supporting initiatives and providing aid to affected communities in Wad Elnimear through the MRC. While these efforts were undoubtedly well-intentioned and aimed at addressing the urgent healthcare needs of those affected by mycetoma, the concentrated focus on Wad Elnimear inadvertently led to the perpetuation of stigma associated with the village. As news of the village’s high mycetoma prevalence spread, Wad Elnimear became a symbol of the disease, further exacerbating the stigmatisation experienced by individuals living there.

Another factor that may have contributed to this reputation and to the stigma, from my own observation, is that most of the patients that had an amputation as a consequence of mycetoma disease were from Wad Elnimear village; I concluded that part of the reason for the increased stigma regarding Wad Elnimear was that although Wad Onsa had also accepted several medical missions from the MCR there was a higher number of amputations in Wad Elnimear, and this lead to increased stigma.

During my fieldwork, I spoke with a mycetoma patient residing in Wad Onsa, the adjacent village. He emphasised his desire that I address him as being from Wad Onsa, rather than Wad Elnimear. It seemed as though he was implying that if mycetoma were to affect individuals from Wad Elnimear, the severity of the disease would increase.

> and my foot got injured while I was playing football with Wad Elnimear.
>
> (Mycetoma patient from Wad Onsa village)

Another patient told me that he believed he had contracted the disease when he was injured playing football with people from Wad Elnimear village, hence, the consequences of this stigmatisation were far-reaching. Beyond the immediate impact on individuals’ psychological wellbeing, it also affected the broader community. Wad Elnimear became synonymous with mycetoma in the public consciousness and this could result in unintended discrimination against the village and its residents. This further compounded the challenges faced by individuals in seeking social acceptance, employment opportunities, and access to resources outside the village. Understanding the interplay between geographic place, stigma, and resource allocation is crucial for formulating effective strategies to address mycetoma and its associated stigmatisation.

Institutional stigma

In my research on mycetoma, I encountered another significant source of stigma that stems from the institutional dynamics within the MRC itself. This form of stigma arises from the centralisation of medical services and the exclusive provision of free mycetoma medication solely within the centre, which is located in Khartoum. While the intention behind centralisation may be to streamline care and facilitate specialised treatment, it inadvertently contributes to the stigmatisation of mycetoma patients.

The centralisation of medical services within the MRC creates a perception that the centre is the only legitimate and authoritative source of treatment for mycetoma; this can also be linked to the health-seeking pathways of mycetoma patients, as individuals seeking care outside of the centre may be seen as deviating from the established norm, which can lead to their stigmatisation. This institutional stigma reinforces the notion that only by receiving treatment from the MRC can patients be recognised as legitimate or worthy of support, further marginalising those who cannot access the centre’s services due to geographical or financial barriers.

Moreover, the exclusive distribution of free mycetoma medication within the MRC supported by the FMOH exacerbates the institutional stigma experienced by patients. By confining the availability of free medication to a single location, individuals who are unable to access the centre are disadvantaged and face additional hurdles in obtaining the essential treatment they require. This practice not only perpetuates inequalities but also reinforces the idea that those outside of the centre are somehow inferior or less deserving of support.

The consequences of this institutional stigma are far-reaching. Patients who are unable to access the MRC may experience feelings of inadequacy, exclusion, and self-blame. They may internalise the belief that their inability to access the centre’s resources is a reflection of their own lack of worth or the severity of their condition, leading to diminished self-esteem and psychological distress. This institutional stigma also has social ramifications, as patients may face judgement and discrimination from their communities, who perceive their inability to access the centre as a failure or sign of inferiority.

Discussion

This study shows that patients with mycetoma are highly stigmatised, even inside a village with one of the highest rates of infection with the disease. There is a notion among some of the villagers that mycetoma is a genetic disease that is transmitted within specific families. This concept relates not merely to the disease alone, but instead, the stigma touches families that have more than one mycetoma relative who has had an amputation. This can open the door for an assumption of some variation in the severity of the disease related to a specific variant of the disease that causes this complication, which needs further study. Stigma in mycetoma varies with the stage of the disease, and with the presence of amputation and an active wound; the discharging of pus and grains are associated with stigma more than are inactive wounds and sinuses.

Both felt and enacted stigma have been observed among people who encounter the disease in Wad Elnimear village; stigma can come from caregivers, families, the community, and even healthcare providers. Mycetoma patients reported overt manifestations of stigma during social events such as funerals, weddings, school events, and prayer and ritual activities. Felt stigma can prove to be a more disruptive factor than enacted stigma. As a direct consequence of discrimination (Scambler et al., 2006), felt stigma places a severe psychosocial burden on the stigmatised, resulting in low self-esteem and self-efficacy, and leading to self-blame, hopelessness, and helplessness (Heijnders & Van Der Meij, 2006; Weiss, 2008). It also pushes stigmatised individuals (and possibly their families) to adopt non-disclosure and concealment of the condition. This may make patients more susceptible to disability, because their access to social, health, and financial resources is reduced or curtailed (Scambler et al., 2006; Weiss & Ramakrishna, 2006). Felt stigma related to mycetoma also has similar negative consequences for the psychosocial wellbeing of affected individuals.

It is important to delve into the topic of stigma beyond the individual level and explore the broader structural implications. In this chapter, I have illustrated how stigma can extend beyond the immediate individual affected by mycetoma and manifest at higher levels within the social hierarchy. Even actions that are well-intentioned, such as repeated medical missions and the attention of NGOs to a particular village, can inadvertently contribute to negative stigma and have unintended consequences, including the potential failure of these interventions, as discussed in Chapter Four.

A village can itself become stigmatised as an area with a high prevalence of mycetoma disease. The continuous presence of healthcare providers and researchers in a village, although aimed at providing support and improving healthcare outcomes, can inadvertently reinforce and perpetuate the stigma associated with mycetoma. This additional layer of stigma can be categorised as a form of ‘structural stigma’, a concept introduced by Link and Phelan to describe the macro-social manifestations of stigma within institutions and systems (Link & Phelan, 2001). While Link and Phelan did not explicitly use the term ‘structural stigma’ to describe village-level stigma in relation to mycetoma, their work provides valuable insights into the distinction between individual and structural stigma, as well as the crucial role played by institutions (Hatzenbuehler, 2016). Link and Phelan recognise that stigma operates not only at the interpersonal level but is deeply embedded within societal structures, including healthcare systems, policies, and cultural norms.

Singer and Baer’s conceptualisation of power dynamics within medical anthropology theory provides valuable insights that can help theorise the dynamics at play in the context of mycetoma. Power, in this context, refers to the ability of individuals or institutions to influence and shape the experiences and outcomes of those affected by the disease. By examining power relations, we can unravel the underlying mechanisms that perpetuate stigma and stigmatisation within the mycetoma landscape.

Drawing upon this theoretical framework, we can analyse the power dynamics at work in the repeated medical missions and NGO attention given to the villages. While these interventions may be well-intentioned, they inherently embody power imbalances that can contribute to the perpetuation of stigma. The concentration of medical resources and expertise within the MRC, situated in the centre of Khartoum, creates a power dynamic where the centre holds significant control over the provision of free mycetoma medication.

This power dynamic reinforces the institutionalisation of stigma as patients are compelled to rely solely on the centre for essential treatment. Those who are unable to access the centre due to geographical or financial constraints find themselves marginalised and further stigmatised. The MRC, as a powerful institution, exerts influence over the narrative and the distribution of mycetoma care, inadvertently perpetuating structural stigma and reinforcing the power imbalance between the centre and the village.

Furthermore, the power dynamics in the context of mycetoma extend beyond the immediate interactions between healthcare providers and patients. They also encompass the broader sociopolitical landscape of Sudan, where healthcare policies and resource allocation reflect underlying power structures. The centralisation of medical services and resources within the MRC reflects a power dynamic that prioritises certain locations and communities over others, perpetuating disparities and reinforcing the stigma associated with the village.

Understanding these power dynamics is crucial for comprehending the broader context in which mycetoma stigma operates. By recognising the influence of power imbalances, we can critically examine the unintended consequences of interventions and challenge the existing structures that perpetuate stigma. This necessitates a comprehensive approach that not only addresses individual-level interventions but also works towards dismantling the structural and systemic factors that contribute to stigma and the unequal distribution of resources.

This stigma can lead to a variety of changes in behaviour and in coping strategies such as avoidance of social gatherings like funerals and weddings, avoidance of attention, dropping out of school, and even staying away from the mosque and religious activities. As shown in Ahmed's story, an individual living with mycetoma may leave their prosthetic leg near the door of the mosque and do their prayers close by the door, without going to the front lines inside the mosque. Livelihoods are also affected, mainly when disabilities occur. This can also lead to relationship disruption for some mycetoma patients and has contributed to divorce and a decrease in self-esteem and an avoidance of getting re-married for both males and females.

Stigma is known to have indirect but strongly negative implications for public health efforts to combat the diseases concerned (Kaur & Van Brakel, 2002; Piot & Seck, 2001; Weiss, 2007; Weiss et al., 2006). Both the personal effects and the damaging public health impact are surprisingly similar for many chronic stigmatised conditions. The impact on the affected individual includes psychological stress, depression and other psychiatric morbidities, fear, marital and relationship problems, other social participation restrictions such as loss of employment or reduced employment opportunities and reduced education opportunities, increased risk of disability and advanced disease (Van Brakel, 2006); moreover, stigma can reduced the likelihood of the patient's persisting with the treatment (Tora et al., 2014).

Many adverse effects on public health programmes and interventions have been reported because of the related stigma. Important examples include delay in diagnosis and treatment, resulting in the continuing risk of disease transmission in the case of infectious diseases and more severe morbidity and poorer treatment prognosis in most conditions (Jaramillo, 1998; Nicholls et al., 2003; Piot & Seck, 2001; Ngamvithayapong et al., 2000). Concealment may result in continued risk behaviour and failure to embrace preventive behaviour, for example, as in conditions such as HIV/AIDS and TB (Adetunji & Meekers, 2001; Rahlenbeck, 2004), and in poor treatment adherence or defaulting from treatment, as has also been reported in the case of leprosy, TB, HIV/AIDS, mental illness, and epilepsy (Weiser et al., 2003). In TB and HIV/AIDS, poor treatment adherence increases the risk of the development of drug resistance (Bangsberg et al., 2000; Bangsberg et al., 2004; Wahl et al., 2000).

In this chapter, I have demonstrated that mycetoma is a disease associated with high levels of stigma. People with mycetoma experience felt stigma as well as the enacted stigma imposed by the community. This has important negative repercussions for their everyday lives, as it affects their work, sex life, religious and social lives among other aspects of their lives. Crucially, however, this stigma is exacerbated by the actions of healthcare providers and policymakers, making it understandable – among other reasons discussed in earlier chapters – that people with mycetoma avoid conventional formal health facilities and instead seek alternative healthcare pathways via traditional medicines and healers.

Chapter Eight

Discussion

Chapter Eight: Discussion

Discussion

Mycetoma management in Sudan exemplifies the complex intertwining of sociopolitical, economic, and cultural elements that global health challenges comprise. Central to this nexus of issues is the role of power, which is manifested in various forms and extends its influence through the intricacies of health policy, treatment protocols, and intergroup relations.

The management of mycetoma in rural Sudan, as in Wad Elnimear, underscores the profound implications of the power differential between the local community, or villagers, and government officials. The dismissal and devaluation of villagers' knowledge and practices by these officials inadvertently contributes to a climate of mistrust. (Lather, 1988) illuminated this point, arguing that such dismissals are a form of social devaluation that compounds power imbalances, thus exacerbating existing disparities. Furthermore, the lack of genuine communication and respect between these two groups generates a self-perpetuating cycle of miscommunication and mistrust, which only serves to further widen the power gap.

The importance of respecting and incorporating indigenous knowledge in health interventions cannot be overstated, a point resonated in the works of Mason Durie (2004). The issue of power recurs here: whose knowledge is considered valid, and whose perspectives matter? Western biomedical interventions are often enacted 'for' the communities involved, implying a power dynamic where the recipient community is passive, and the Western actors are the active agents. The alternative is to provide interventions 'with' the communities, where power is shared, and local communities actively participate in the decision-making processes. Such an approach not only mitigates the power imbalance but also improves the effectiveness of the interventions by ensuring that they are culturally sensitive and contextually appropriate.

Further compounding this situation is the lack of a national mycetoma policy in Sudan. The criteria for public health prioritisation are largely determined by epidemiological data, a practice that underscores the influence of power in shaping health agendas. Illnesses like TB and malaria, which have well-established epidemiological data, receive the lion's share of resources, leaving less 'visible' diseases such as mycetoma in the periphery. Here, power is exercised through the lens of epidemiological visibility, aligning with Barasa et al.'s (2016) observations about power dynamics in health priority settings. Moreover, the majority of this information is generated by the most dominant actor in the field of mycetoma in Sudan, which may explain the fact that the sole policy document regarding the disease was produced by the Mycetoma Research Centre (MRC) and has not yet been published.

In exploring the complexities of mycetoma management, the artificial animal enclosure project emerges as a pivotal case study (see Chapter Four), offering profound insights into the interplay of local practices, governmental interventions, and health outcomes, underscored by significant power dynamics. This project, initiated with the intention of reducing mycetoma incidence in endemic regions, serves as a unique lens through which we can examine the intricate dynamics that underlie public health initiatives. It is particularly relevant in illustrating how health strategies, even when well-intentioned, may falter if they fail to align with the lived realities and cultural contexts of the target communities, and if they do not adequately address the inherent power imbalances between these communities and the implementing agencies. The project's approach and outcomes provide a crucial understanding of the challenges faced in the management of neglected tropical diseases (NTDs), especially in regions where resources are scarce, traditional practices are deeply ingrained, and power differentials significantly affect health outcomes.

The relevance of this project lies in its illustrative example of the consequences when top-down health interventions overlook or misunderstand the needs and values of local populations, often exacerbated by the power imbalances between policy-making entities and the communities they serve. In the case of mycetoma, a disease that predominantly affects rural and often marginalised communities, the lessons learned from the animal enclosure project are particularly pertinent. They highlight the necessity of engaging with and respecting local knowledge and practices in the design and implementation of health initiatives while consciously navigating and mitigating the power dynamics at play. This project, therefore, not only informs our understanding of specific health interventions but also broadens our perspective on the broader strategic approach required for effective NTD management, a perspective that is critically needed in the ongoing efforts to combat mycetoma.

The project revealed a stark contrast in perceptions between government officials and the local villagers, underlined by a power struggle. Government representatives viewed the project's failure as resulting from villager ignorance and non-compliance, effectively asserting the officials' power and authority; in contrast, the villagers pointed to structural, social, and cultural barriers unrecognised or dismissed by the officials, indicative of the locals' marginalised position in this dynamic. This misalignment echoes similar challenges in mycetoma management, where disconnects between policymakers and affected communities can lead to ineffective health interventions, often due to unaddressed power differentials.

The project's shortcomings highlight not only the necessity for culturally sensitive approaches in health interventions but also the need to confront and address the power imbalances that often dictate these interventions. For NTDs such as mycetoma, integrating local knowledge and practices is essential for the success of management strategies, necessitating a more participatory approach where community engagement is central to the design and implementation of health solutions. Such an approach not only fosters effectiveness but also works towards levelling the playing field in terms of power and influence in public health decision making.

At the national policy level, the absence of specific policies regarding mycetoma reflects a significant gap. This gap may stem from a combination of factors including the rarity of the disease, lack of awareness, and limited resources. The lack of national policies contributes to the invisibility of mycetoma and the marginalisation of affected individuals. It can also inhibit the integration of mycetoma management into broader health systems, making it challenging to ensure comprehensive and coordinated care. The development of national policies could play a vital role in legitimising and prioritising mycetoma as a public health concern, mobilising resources, and coordinating efforts among various stakeholders.

However, in developing such policies, it is important to ensure that they are not merely top-down impositions but are informed by the lived experiences and perspectives of affected communities. Policies should aim to address the sociocultural dimensions of mycetoma, including stigma and traditional healing practices, alongside the biomedical aspects. Engagement with a wide range of stakeholders – including community members, traditional healers, healthcare providers, researchers, and policymakers – will be crucial in this process.

Where policies fail to consider input from a wide range of stakeholders, this could also add to the power of the biomedical model of Western medicine – represented not only by the MRC – over the traditional healing system, the two major systems in the mycetoma management landscape. However, there is a clear power dynamic favouring the Western model, often leading to the marginalisation of traditional practices. This power dynamic is reinforced by factors such as the colonisation of healthcare institutions, Western pharmaceutical companies' influence, and the preponderance of Western biomedical practices in healthcare settings (Jelinek & Neate, 2009).

This dynamic has implications for the local communities in Wad Elnimear, with local knowledge and practices often being disregarded in favour of Western biomedical approaches. Patients seeking care at the MRC often lament the lack of social support and the disregard for sociocultural and economic factors that influence mycetoma's spread. This is evident in how the MRC's Western-centric approach tends to create a power dynamic that undermines doctor–patient relationships and cultural beliefs.

Despite the significant strides biomedicine has made, its dominance in the treatment of mycetoma raises questions about the presence of power dynamics in global health practices. The potential marginalisation of indigenous healing practices in favour of Western biomedical approaches underscores a form of epistemic injustice, where local knowledge systems are dismissed or trivialised. This phenomenon further intensifies power differentials, privileging Western perspectives while neglecting the sociocultural realities of the affected communities.

Furthermore, an overemphasis on biomedical models of care may result in doctor–patient relationships that reflect and reproduce power imbalances, thereby further alienating patients. In contrast, the role of traditional healers in Sudanese communities underscores a local, culturally congruent response to mycetoma. Their enduring presence and acceptance within these communities highlight the importance of integrating local healing practices into broader health interventions.

In many cases, these two systems may be seen as conflicting due to differences in ontology, methodology, and epistemology. The biomedical model often holds a position of power due to its association with modernity, sophistication, and universality, which may result in the marginalisation of traditional healing practices. However, this dynamic perhaps ignores the potential value that traditional healers bring to community health and to the management of mycetoma specifically. Traditional healers' knowledge of local sociocultural dynamics and their perceived legitimacy within the community could be leveraged to facilitate community engagement, awareness campaigns, and patient support, thereby bridging the gap between communities and the biomedical healthcare system (WHO, 2002).

A key point of critique is the potential ethnocentrism involved in the predominance of the Western biomedical model, which can lead to a lack of cultural sensitivity in healthcare delivery. There may be an unconscious bias towards viewing Western medical practices as inherently superior to traditional practices. While Western medicine has indeed made significant strides in the management of diseases, it is crucial not to overlook the value and significance of traditional practices, especially in the context of marginalised communities.

I will also add that the MRC wields significant power in the mycetoma-management landscape. This centre is recognised as the primary source of specialised care for mycetoma patients, partly due to its centralisation of services and exclusive provision of free medication. This dominance is reinforced by the endorsement of the State Ministry of Health (SMOH) and the international research community, represented by organisations such as the WHO. However, the MRC's authority in mycetoma management may inadvertently marginalise patients who are unable to access its services due to geographical or financial barriers. Moreover, it creates a hierarchical perception that positions the MRC as the sole legitimate and authoritative source of mycetoma treatment, thereby shaping health-seeking behaviours and potentially contributing to institutional stigma. While the MRC's contributions to mycetoma research and management are invaluable, it is vital to recognise and address the potential implications of this power dynamic.

An important finding in this thesis is that the stigma associated with mycetoma significantly influences the health-seeking pathways of individuals affected by the disease. Stigma takes various forms: felt, enacted, structural, and institutional. Felt and enacted stigma are often experienced by individuals during social events and interactions with healthcare providers, affecting their self-esteem, self-efficacy, and psychosocial wellbeing (Heijnders & Van Der Meij, 2006).

Structural stigma plays out at the village level, with Wad Elnimear often being singled out due to its high prevalence of mycetoma. This village-wide level of stigmatisation affects individuals' social acceptance, employment opportunities, and access to resources outside the village. Institutional stigma is also experienced, stemming from the centralised service delivery and exclusive provision of free medication at the MRC. This form of stigma may reinforce the perception that only those accessing MRC services are worthy of support, further marginalising individuals who cannot access the centre's services due to geographical or financial constraints.

Individuals with mycetoma are highly stigmatised, even inside one of the villages with high prevalence. There is a notion among some of the villagers that mycetoma is a genetic disease that is transmitted through specific families. This concept does not relate to the disease alone; rather, the stigma affects families with more than one mycetoma relative with amputation. This can then open the door for an assumption that some varieties of mycetoma may have different levels of severity, as dependent on the varying genetics of the microbes or the host, which may need further study.

Mycetoma-related stigma varies with the stage of the disease, so that individuals suffering either amputation or an active wound that discharges pus and grains experience more stigma than do others. Both felt and enacted stigma have been observed in the research context setting. Stigmatisation can be experienced emanating from the different social layers of caregivers, families, generalised community, and even healthcare providers. Indeed, mycetoma patients have reported overt manifestations of stigma during social events such as funerals, weddings, school events, and prayers.

Utilising a qualitative approach provides a broader opportunity to explore nuanced perspectives in greater depth. In this study, we have drawn heightened attention to the importance of traditional healers in the treatment of mycetoma, as they are the first point of contact for almost all patients in Wad Elnimear village.

In this study, I support the concept that some of the patients employ only one health system or treatment modality at a time; Kunna and his colleagues have also reported on this, but the magnitude of this phenomenon is actually more remarkable than their reports have ascertained, as only 4 per cent of the patients from their study data were asked to abandon their own allopathic medication by the traditional healers (Kunna et al., 2021c). The involvement of two systems for treatment at one time is also reported in this study. Several factors appeared to justify this action, principally as mycetoma patients were doing whatever they could to treat the disease, and most especially as there is neither a definitive treatment for mycetoma, nor a definitive diagnostic modality (Ahmed et al., 2017; Emmanuel et al., 2018a). In addition, the long duration and the chronicity of both the disease *and* the biomedical treatment pathways for the disease play an additional role in the medication’s side effects and the high rates of disease recurrence.

Some researchers have argued that, in Africa, it is mainly poor and less-educated people who seek care from traditional healers, because they offer treatment at lower cost and are easier to access (Labhardt et al., 2010). This assumption is also held by many of the healthcare providers offering biomedical mycetoma treatment. There is an ongoing, common assumption among researchers and policymakers regarding the use of traditional medicine, maintaining that poor and marginalised people are most reliant on traditional medicine due to its low cost. This study challenges those assumptions by showing that there are additional factors that contribute to these treatment choices. Furthermore, some of the individuals affected by the disease travel long distances seeking traditional healers' opinions. In research that supports our results regarding patient-choice, studies in Cameroon on the treatment of epilepsy have shown that patients deliberately choose traditional care, even though it is 20 times more expensive than Western medical treatment (Njamnshi et al., 2009; Preux et al., 2000).

Equally, a policy document search reveals that there is no official published policy regarding mycetoma and its management in Sudan. In the absence of a precise case definition and field-friendly diagnostic tools, mycetoma cases and variants are not well understood. Despite Sudan's likely having the highest prevalence of mycetoma worldwide (Van de Sande, 2013), mycetoma has not been a priority for the Federal Ministry of Health (FMOH) of Sudan. Indeed, it was only in 2015 that the Department of Communicable and Non-Communicable Disease Control of the FMOH initiated a policy formulation for NTDs and malaria at the national level. However, this still does not include specific mycetoma plans.

The only policy guidelines available that are dedicated to mycetoma were prepared by the MRC. The document, entitled 'Mycetoma policies and management guidelines for service provision and essential good clinical practice 2017', draws on 25 years of experience in the management of mycetoma patients at the centre. It sets out three main strategic objectives for tackling mycetoma: improving access to treatment, ensuring high service quality, and bridging the knowledge gap. It should be noted that these guidelines are based on experience of treating only those patients who *reach out* to the MRC. Additionally, there is no indication of government endorsement of the guidelines.

Data from the interviews conducted here has revealed that, although there is an official government commitment to formulating a policy regarding NTDs, health ministry stakeholders do not always align with this commitment. One high official of the FMOH opined that, although mycetoma may be disabling, it is not a fatal disease, and, furthermore, that there is a lack of both clear case definition and sufficient data on incidence and prevalence. Therefore, this official argued, mycetoma does not deserve the same level of importance as is given to other, non-neglected, diseases.

It is hardly surprising that this official does not see mycetoma as a priority for their department, as it is apparent that, in Sudan, among the actors working within the field of mycetoma in Sudan, the MRC is by far the most powerful organisation. Both national and international agencies that are interested in mycetoma carry out their work through the MRC; for example, the FMOH itself donates free medication to the MRC, which is then dispensed to individuals affected by the disease who attend the MRC clinic. The MRC leadership has global connections, and many international actors work directly with the MRC, bypassing the FMOH. The MRC receives substantial international funding, and collaborates with various UN organisations and international universities. It is apparent that this relative exposure and importance of the MRC is behind much of the tension that is then created between the centre and FMOH officials.

The international actors that work in the field of mycetoma in Sudan all work through the MRC. For example, the Drugs for Neglected Diseases initiative (DNDi) supports the MRC in conducting randomised control trials to test new mycetoma therapies, and the Japan International Cooperation Agency (JICA) provides artificial limbs for patients through collaboration with the MRC. The MRC also receives multiple donations from private companies. An engineering company, as its ‘social accountability activity’, donated 72 modern animal enclosures to villagers in mycetoma-endemic areas, free of charge, so as to improve the overall village hygiene and to reduce the levels of contact with animals and their excreta. The MRC has a strong portfolio of international academic networking, and partnerships with several international institutes as well, including: Brighton and Sussex Medical School (BSMS) in the United Kingdom, Erasmus University Medical Centre in Rotterdam in the Netherlands, and the University of Tours in France. These growing partnerships support research and training activities, including postgraduate studentships.

Rather than making provisions to the FMOH, both the Sudanese government and international donors distribute resources directly through the MRC. As a result, the FMOH is left with minimal power regarding mycetoma, and this has contributed to tensions between the MRC and the FMOH. Several federal officials have pointed out that the MRC is seen as representing the national problem of mycetoma, yet does not have access to the full, nationwide knowledge *about* mycetoma, as there are no data available to them regarding those patients for whom they do not have responsibility, nor concerning the quality of their care. Another official pointed out that the success of the centre means that mycetoma treatment is neglected across primary health services. On the other hand, researchers from the MRC have expressed frustration about a perceived lack of interest in mycetoma at the FMOH.

The evolution of the MRC from its inception as a small-scale clinic within the Soba University Hospital to its current status as a WHO Collaborating Centre is a microcosm of the global shift in perceptions and strategies for the management of NTDs. This transformation is emblematic of the broader journey of NTDs from the periphery to the centre of global health priorities. Initially, the MRC's focus on surgical interventions mirrored the limited scope and resources typically allocated to NTDs, reflecting a period when such diseases were often overlooked in the broader public health discourse. However, the centre's growth and eventual recognition by the WHO mark a significant milestone, signalling a growing awareness and commitment to addressing these diseases, which disproportionately affect the most marginalised communities. The MRC's journey from being a local initiative to an internationally recognised centre underscores the increasing global acknowledgment of the impact of NTDs and the need for dedicated research and treatment centres.

The MRC has what has been conceptualised as 'dispositional power' in Sudan (Arts & Jan Van, 2004). This is power resulting from actors' being placed in certain positions that make them more influential than others involved in the issue in question. We may say that the MRC has dispositional power in Sudan through its greater connectivity with international stakeholders, and subsequent access to resources.

The source of the dispositional power of the MRC is linked to the fact that they have more authoritative medical 'legibility' in the eyes of the supra-national bodies than that which is attributed to the national body by these same supra-national stakeholders. This is connected to Scott's (1998) concept of 'legibility', which refers to how modern states of all persuasions have sought to make their populations more 'legible' to government. It has been suggested that, increasingly, the necessity for 'legible' populations and health systems has been extended beyond national government. Supra-state institutions, such as the World Bank, the WHO, and multinational companies engaged in the health sector, increasingly demand 'legibility'. Within Sudan it is the MRC, rather than the FMOH, that currently has the capacity to produce a legible account of, and subsequent treatments for, mycetoma populations.

We can, at the same time, view the individual as having the illness because the community is not ready to accept him, and, additionally, then argue that the community does not accept him/her because the available healthcare providers are not yet ready to address this individual's concerns and needs. Equally, it can be argued that this is because the disease is not broadly accepted, and that it is neglected at the macro level, because there are currently no published policy guidelines concerning mycetoma, and even the policymaker and the decision maker are still not ready to make mycetoma a priority. This extends further, as the country where the disease is most highly reported, Sudan, is not yet prepared to make the disease a priority, and the chain of negligence is connected across all of these levels of influence, from higher up at a global level, all the way down to the individual, when either addressing or expressing his/her own views and experiences as a mycetoma patient. Hence, the issue of this negligence is seen across almost every level of the healthcare system, from the higher level of the capitalist world system, through each policy and actor that is a decision maker, and even at the institutional levels. Although it differs from level to level, this form of neglect is systemic, involving the policies of government(s) and private organisations that, either intentionally or unintentionally, exert power over the individual at the micro level. Examples include the centralisation of medical services, and even the medication that is distributed free of charge, but only inside the MRC, which can be viewed as a form of institutional discrimination and stigmatisation for mycetoma patients when contextualised within the political and economic situation in Sudan. This is in addition to the negligence by the healthcare providers in the MRC for the *social aspects* of the mycetoma patients' required care, which has led to the frustration of their mycetoma patients to the extent that they often return to seeking disease-management advice from the traditional healers, and even undertake increased travel in order to seek this advice. NGOs can also, in indirect ways, play a major role in adding to this negligence through their collaboration with the MRC. Through such involvement, the NGOs add to the power of the centre, to the extent that it exceeds the power of the FMOH as the main coordinator of mycetoma treatment across the country. This shift of power minimises the role of the ministry, and contributes to the domination of the MRC as the most powerful player, not only in Sudan, but also in the region (see Figure 30).

A political economic analysis of contemporary infectious disease must go beyond the broad social determinants of sickness to consider the *beneficiaries*, that is: "those who benefit from the inequalities that kill" (Navarro, 2009: 440). Those who profit from inequality, Vicente Navarro stresses, are the dominant and most powerful social classes. In both rich and poor countries alike, they are those that accumulate wealth for their own benefit, rather than allowing the world's wealth to benefit the wellbeing of all of humanity, or, indeed, all of Earth's biologically diverse inhabitants. As Charles Briggs and Clara Mantini-Briggs also emphasise, infectious disease epidemics: "are 'mirrors held up to society,' revealing differences and power as well as the special terrors that haunt different populations" (2004: 8).

The impact of political instability on life in Wad Elnimear

In recent years, the anthropological approach has demonstrated the value it contributes towards the understanding of and response to certain diseases, such as: HIV, Ebola, SARS, tuberculosis, malaria, influenza, and kuru. This contribution has fundamentally derived from analysis of the role of such diseases in the creation of lived experiences, and as reflections in *physical bodies* of conflicts and points of tension in *social bodies*, as well as through the identification and assessment of human behaviours linked to both prevention and treatment. Anthropology can nest every-day, on-the-ground activity within the encompassing frames of social groups and communities and, beyond this, within the bigger picture of global processes and international social relationships. Its scope broadens even further to explore the linkages – not readily apparent, yet critically important – between microscopic entities and the political and economic structures of human societies, fundamentally by identifying the pathways that connect human bodies, cultural and social systems, and health (Singer, 2015).

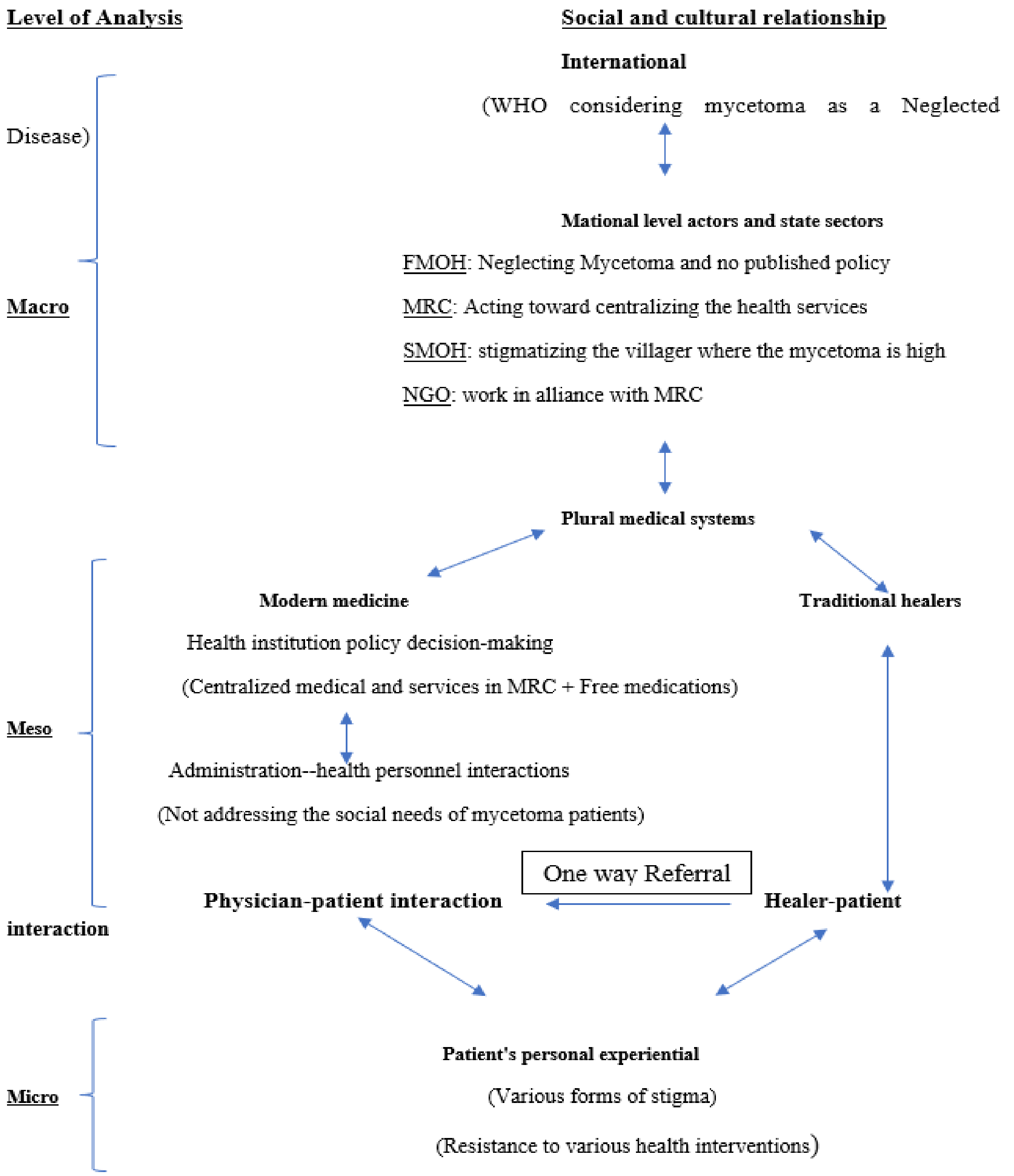

Figure 30: Negligence across all levels of the health system in terms of mycetoma and its management in Sudan.

The anthropological approach to HIV disease demonstrates its particular contribution to the larger multidisciplinary study of infectious diseases. International health programmes invest considerable effort into two areas of research. Firstly, they examine risk behaviours, focusing on individuals as rational decision makers, and interpreting behaviours as a direct (and logical) outcome of an individual's characteristics or capacities. For example, whether someone is likely to engage in sexual behaviours considered riskier for contracting HIV is frequently analysed in terms of an individual's characteristics, such as: their sexual orientation, knowledge, attitudes, and their perceived ability to prevent infection. Secondly, these health programmes look at the structural vulnerabilities of entire populations, for example, the role of poverty in risk behaviours. By contrast, one important focus of anthropology has been the relationship between individual agency and structural factors in health, that is, the multiple levels that encompass and define social groups, interpersonal networks, and communities. Moreover, anthropologists move beyond the simplistic understanding of individuals as rational decision-making agents, recognising, instead, that people's behaviours are not the direct product of their individual characteristics, decisions, or capacities. Rather, behaviour, including action that puts people at risk of infection: "is always itself social, imbued with meaning, rich in significance, and the outcome of a variety of forces" (Kippax, et al., 2013). One of these 'forces' is people's individual involvement in social groups, which, in turn, critically influences their subsequent identities, values, knowledge, health status, and activities. For example, sociocultural groups that view the primary role of sex as being an act of procreation, do not receive favourably public health messages promoting the use of condoms to prevent HIV infection. Group membership also mediates awareness of, and attitudes towards, particular infectious diseases, as well as then co-defining the 'appropriate behaviours' to avoid or treat them, however they are understood, which may have nothing to do with notions of microbial infection. Group membership also influences the emergence of specific social responses to particular infectious diseases, such as the kinds of community organisation that have emerged worldwide around HIV disease.

Critical medical anthropology, which is conceptually linked to eco-social theory in epidemiology, views health as being an expression of social relations within society, and, especially, of the ways that social inequality structures health disparities and vulnerability, patterns of morbidity and mortality, and contributes not only to the social distribution of disease-related social suffering, but also to health-related resilience, agency, and social action.

The political instability within the country of Sudan affects the cultural habits of residents in Wad Elnimear village. This is evident to the extent that they exchange the gas used in their cooking for wood with which to make their cooking fires instead. This wood is an import that comes from trees outside the village, and it is the responsibility of the women to fetch it. This task increases the probability of their getting an injury, and hence facilitates the entrance of the microbes causing mycetoma into the body and the subsequent occurrence of the disease.

The same political instability and economic circumstances have also led to changes in the types of animals that are owned by each villager. Instead of only breeding cows, people in Wad Elnimear have switched, over a relatively short period of time, to also having goats in compensation, so as to preserve one of the dominant cultural and social values of slaughtering an animal and giving the meat as a sign of hospitality. This particular change was missed during the design of the artificial animal enclosures as a health intervention for that particular village.

Concluding thoughts

This study may serve as a starting ground for any upcoming intervention dealing with the disease of mycetoma, or similar NTDs, and will assist towards a socially and culturally sensitive intervention. It will also provide a guide for designing a prevention plan for mycetoma, while considering the involvements of different levels of both policymakers and decision makers. In addition, it usefully outlines the different treatment systems, without ignoring the voice of the community and those who are most affected by the disease.

The management of mycetoma, particularly within the Sudanese context, is emblematic of a larger narrative of systemic neglect that pervades the realm of NTDs. This argument is underpinned by the observation that despite the obvious attention mycetoma now receives in the spheres of global health policy, research funding, and public health initiatives, these interventions have not yielded the intended outcomes, and mycetoma still imposes a substantial burden on affected populations. The persistent under-representation of mycetoma in these critical areas is not merely a reflection of resource allocation but also indicative of deeper socio-economic and geopolitical disparities that inform global health priorities and influence approaches to health interventions.

This research further posits that the interplay of power dynamics between various stakeholders – including international health organisations, national health policymakers, local health practitioners, and communities – shapes the landscape of mycetoma management. The power disparities evident in the interactions between these actors contribute to a fragmented healthcare system where traditional practices and local knowledge are often marginalised. This imbalance has tangible repercussions for the accessibility and effectiveness of mycetoma treatment and prevention strategies, as the value of integrating diverse medical systems and the potential benefits of a more collaborative approach are subsequently overlooked.

The stigmatisation associated with mycetoma compounds the challenges faced by patients. Stigma not only reinforces the cycle of neglect by deterring individuals from seeking care but also exacerbates the social isolation of sufferers, thereby limiting the success of any intervention strategies. The insidious nature of stigma, rooted in cultural perceptions and reinforced by systemic inequities, demands a proactive and multifaceted response that goes beyond medical treatment to address the social determinants of health.

The stigmatisation of mycetoma has emerged as a profound barrier to effective disease management and patient wellbeing. Stigma not only impedes individuals from seeking timely medical care but also contributes to a cycle of psychological distress and social isolation. Addressing this stigma requires concerted public health messaging, community engagement initiatives, and policy interventions that recognise and actively combat the roots and repercussions of stigma. The transformation of perceptions of mycetoma at the community level can pave the way for a more inclusive health system that upholds the dignity and rights of all patients.

The thesis argues that as an unsuccessful implementation of a health intervention, the artificial animal enclosure project serves as a case study highlighting the broader issues at play in NTD management. Such interventions often fail due to a lack of congruence with local realities and a top-down approach that does not engage meaningfully with the community. To rectify this, there must be a concerted effort to reshape the conceptualisation of mycetoma and its management by national policymakers to align with the lived experiences of those affected. This calls for a paradigm shift towards a health system that is not only responsive but also inclusive and equitable, ensuring that no patient, community, or disease remains in the shadows.

The analysis of the artificial animal enclosure project has provided critical insights into the factors contributing to global health intervention failures. It serves as a cautionary tale of how even seemingly well-designed and well-intentioned projects can fail without thorough understanding of and engagement with the target community’s context. This finding has significant implications for public health policy and practice: it calls for a shift towards participatory planning and implementation processes that involve beneficiaries at every stage. Such inclusive strategies are essential to ensuring the sustainability and success of health interventions, particularly in settings with limited resources and infrastructure.

In conclusion, this research has illuminated the multifaceted healthcare systems managing mycetoma in Sudan, revealing a complex web of power dynamics and inter-relationships. Through this exploration, we have identified not only the central role of institutions such as the MRC but also the vital contributions of traditional healers and the community’s own health practices. This underscores the need for an integrated healthcare approach that bridges modern and traditional systems, fostering cooperation over competition, and synergy over siloed efforts. Acknowledging the different sources of medical authority and the potential for collaborative dynamics could significantly enhance the effectiveness of mycetoma management and patient outcomes.

Finally, this research has highlighted the disconnect between the conceptualisation of mycetoma by national policymakers and the realities on the ground. It is clear that for public health policy to be effective, it must be informed by and responsive to the lived experiences of those it intends to serve. The findings of this study advocate for a reorientation of research priorities to focus on building robust, context-sensitive health systems that are equipped to address NTDs such as mycetoma. In doing so, we not only advance the cause of global health equity but also affirm the intrinsic value of each individual affected by these often overlooked diseases. As we move forward, it is imperative that the lessons learned from this research inform both current and future efforts to combat NTDs, ensuring that no patient, community, or disease remains neglected.

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Appendices

- Appendix 1: Ethical approval by the Soba Teaching Hospital, University of Khartoum.
- Appendix 2: Ethical approval by Brighton and Sussex Medical School (BSMS) Research Governance and Ethics Committee (RGEC).
- Appendix 3: Participation consent form.
- Appendix 4: Participant information sheet.
- Appendix 5: Fieldwork risk assessment for COIVD 19 pandemic.
- Appendix 6: Letter of ethical approval from Soba Center for Audit and Research (SCAR) committee to continue the fieldwork in Sudan.
- Appendix 7: Ethical clearance to commence my fieldwork from Brighton and Sussex Medical School Research Governance and Ethics Committee (RGEC).

Soba Center for Audit & Research

Study or project name: Socio-cultural and Policy situation of Mycetoma in Sudan: A critical exploration.

Short name:

Primary Investigator (PI): Dr. Mohamed Nasr Mohamed Ahmed Elsheikh.

Affiliation of PI: Mycetoma Research Center - Brighton and Sussex Medical school.

Site of the study: Sudan - Sinnar state.

Date of Submission: 27.12. 2018

Dates for data collection: Jan. 2019

Description of the research: Proposal attached.

Contact no: +249 999219909

Make sure to submit :

1. Full proposal. ✓
2. Consent Form . ✓
3. Agreement from co supervisor from soba if your supervisor is not from Soba Hospital or university of khartoum

Research team

	Name	Role
1.	Prof. Ahmed Hassen Fahal	Superviser
2.	Dr. Shahaduz Zaman	External supoviser
3.	Dr. Mei Truba	External superviser
4.	Dr. Mohamed Nasr Elsheikh	PhD. student
5.		
6.		

	Effect of research on participants and hospital	√ or X	Note
1.	History & Physical from patients	✓	
2.	Blood sampling	X	
3.	Imaging	X	
4.	Special procedure	X	
5.	Risk of the procedure	X	
6.	Administration of medication	X	
7.	Storage of sample	X	
8.	Any financial burden on the participant	X	
9.	Any clinical benefit for the participants	✓	
10.	Any financial burden on the hospital	X	
11.	Any benefit for the hospital	X	
12.	Anything to disclose	X	
13.	Other		
14.	Other		
15.	Other		

Please make sure you submit

Full Proposal ☑ Consent form ☑

For SCAR		
RIB Number	20181227	
Proposal enclosed	[✓ Yes] No	
Consent	[✓ Yes] No Waived	
Overall		
[✓ Approved]	Rejected	Need further assessment
Notification	Outpatient department	
Dr. Ihab B Abdalrahman	Signature	

Final decision by Administration

[✓ Approved] Rejected Need further assessment

Dr Shadad Mahmmoud

Deputy Manager

30/12/018

Ethical Review Application (ER/BSMS9DHJ/9) Mohamed Elsheikh

Project Title	Socio-cultural and policy situation of Mycetoma and it is management in Sudan: A Critical Exploration
Status	Approved
Email	bsms9dhj@central.susx.ac.uk
Phone No.	+249999219909
Applicant Status	PG (Research)
Department	Brighton and Sussex Medical School
Project Start Date	01-Oct-2018
Project End Date	30-Sep-2021
External Funding in place	Yes
External Collaborators	Yes
Funder/Project Title	
Name of Funder	National Institute For Health Research
Is this an IRP project?	No

Ethical Review Application ER/BSMS9DHJ/9 (continued)

Project Description

Mycetoma is a neglected tropical disease. It is a granulomatous inflammatory in nature caused either by bacteria (actinomycetoma) or fungi (Eumycetoma). It starts most likely from minor trauma; it may then spread slowly to evolve deep tissues like bones. Although the foot is the most affected part, the infection can affect all parts of the body. Mycetoma more often occurs in tropical and subtropical regions between latitudes 15° south and 30° north. It is endemic in various countries across the globe Sudan is the most affected part of the globe; still, the prevalence of Mycetoma is unknown, the management is not uniform, No preventive or control program, no early case recognition or surveillance system. Moreover, all the knowledge regarding the socio-cultural understanding is only limited to published case reports and passive case detection. There is no study in Mycetoma addressing the socio-cultural aspect of the disease in a detailed qualitative way.

This study will be the first of its type in Sudan to explore the disease and compacting it in individuals experiencing the illness, their families, the community and health care providers as well as the key service providers, using medico anthropological view. It will provide a better understanding of the community perspective and identifying the gaps between all these layers to suggest a preventive strategy for Mycetoma involving all stakeholders and considering the need and behavior of community and individuals within their context and culture

Aims:

To understand how the actors at different levels conceptualize and seek to manage Mycetoma to recommend sustainable strategies to prevent the disease.

Specific research questions:

How is the disease and combating of it, is currently conceptualized by key actors at national, community and individual levels? What strategies are currently being employed by the different actors in national, community and individual levels?

Explore what strategies can be used for prevention of the disease in Sudan.

We anticipate that our findings will contribute to the understanding of the disease from social, cultural and policy perspective that will help to identify gaps and to recommend an effective community prevention strategy of Mycetoma in Sudan.

This project we will approach disease conceptualization from deferent layers: The Macro level (National); all national document regarding Mycetoma; National health policies, strategies and guidelines will be collected, reviewed and analyzed to address the current conceptualization of the disease in addition to interviewing the national key actors. The Meso level (Community): Community leaders, key implanter and practitioner from Government, private, NGO in national, regional, provincial and community level will be interviewed to understand their knowledge and attitude toward mycetoma. Micro-level (Individuals); the investigator will be observing and socializing in an attempt to study the experience of patients affected with Mycetoma and to develop an emic view toward their illness. and lastly finding the gap between the three levels and designing a community-based intervention and strategy

This work is a collaboration between the Mycetoma Research Centre (University of Khartoum, Sudan) and Brighton and Sussex Medical School

Roles (ER/BSMS9DHJ/9)

Please list all investigators in this project's research team. If you specify role "Other" for any investigator please provide further details in the "Comments" field.

Role	Name	Email	Phone	Institution	Comments
Student	Mohamed Nasr Mohamed Ahmed Elsheikh	almohamed1991@gmail.com	+249999219909	Brighton and Sussex Medical School	Medically qualified PhD student registered at BSMS and based in Sudan
Supervisor	Mei Trueba	M.Trueba@bsms.ac.uk		Brighton and Sussex Medical School	PhD co-supervisor. Lecturer in Global Health at the BSMS, extensive research experience in NTDs, with a particular focus on social determinants and health management
Supervisor	Shahaduz Zaman	S.Zaman@bsms.ac.uk	+249999219909	Brighton and Sussex Medical School	Lead Supervisor for Dr Elsheikh, Senior Lecturer in Social Science at Brighton and Sussex medical school. He has an interdisciplinary background with degrees in Medicine, Public Health, Medical Anthropology

Supervisor	Ahmed Fahal	ahfahal@hotmail.com	+249912346703	Mycetoma Research Center	Sudan based Supervisor. A world expert on mycetoma and Director of Mycetoma Research Center

Ethical Review Form (BSMS version) (ER/BSMS9DHJ/9)	
Question	**Response**
>> Checklist	
C1. Will your study involve participants who are particularly vulnerable or unable to give informed consent or in a dependent position (e.g. children under 16, individuals with learning difficulties, mental health problems, people in care facilities or over-researched groups)?	No
C2. Will participants be required to take part in the study without their consent or knowledge at the time (e.g. covert observation of people in non-public places), and/or will deception of any sort be used?	No
C3. Will it be possible to link identities or information back to individual participants in any way? Will it be impossible to ensure that identities or information cannot be linked back to individual participants in any way (including after anonymisation?)	No
C4. Might the study induce psychological stress or anxiety, or produce humiliation or cause harm or negative consequences beyond the risks encountered in the everyday life of the participants?	No
C5. Will the study involve discussion of sensitive topics (e.g. sexual activity, drug use, ethnicity, political behaviour, potentially illegal activities)?	Yes
C6. Will any drugs, placebos or other substances (such as food substances or vitamins) be administered as part of this study or physiological interventions or processes outside of standard practice and will any invasive or potentially harmful procedures of any kind will be used?	No
C7. Will your project involve working with any substances and / or equipment which may be considered hazardous, e.g. such as radioactive materials?	No
C8. Will financial inducements (other than reasonable expenses, compensation for time or a lottery / draw ticket) be offered to participants?	No
C9. Will the research involve storage and/or analysis of human biological tissue ?	No
C9a. If you answered Yes to question C9, will this be carried out under University of Sussex HTA license?	No
C10. Is there a possibility that your investigations might uncover unexpected and possibly clinically relevant findings?	Yes
C11. Will the study include groups where permission is normally required for access to its members, for example groups based in the community, traditional communities or school pupils?	No
>> Section 1. Methodology, Data Collection and Analysis (Please provide full details)	

1.1. What is the principal research question/objective? Please clearly state the hypothesis to be tested. Please put this in language comprehensible to a lay person.	This project is aiming to understand how the actors at different levels conceptualize and seek to manage Mycetoma in order to recommend sustainable strategies to prevent the disease. Specific research aims: 1- To investigate how Mycetoma and its management has been conceptualized at the national and international policy level. 2- To explore the socio-cultural construction of Mycetoma at the community level. 3- To assess the existing strategies taken to prevent the disease. 4- To explore the embodied experience of the individuals who suffer from Mycetoma. 5- To develop a culturally sensitive strategy for Mycetoma prevention. As this is an exploratory project through ethnographic research approach no hypothesis has been determined beforehand. Rather a hypothesis will be generated through the project
1.2. What research method(s) do you plan to use; e.g. interview, questionnaire/self-completion questionnaire, field observation, audio/audio-visual recording?	This will be a qualitative study with an ethnographic approach. We will be using In-depth interview and Focus Group Discussion guidelines, as well as participant observation checklist. We will be flexible regarding the data collection process.
1.3. How many people do you envisage will participate, who are they (e.g. age and gender) and how will they be selected?	The respondents of this study will be individuals affected with Mycetoma in and their family members as well as community members and decision makers of the small village called Wad Elnemir located in the Sinnar State in the southeast of Sudan Dhaka. As per the tradition of the qualitative research, we will be flexible in terms of the number of respondents. The number will be determined through the principle of saturation and diversity. The data will be collected till data saturation is reached. We will ensure diversity of the respondents in terms of age, gender and socioeconomic condition.
1.4. Please state the rationale for the number of participants to be recruited (please note that it is unethical to recruit either more, or less, participants than required to adequately power a study).	As per the tradition of qualitative research, we will be flexible in terms of the number of participants. The number will be determined through the principle of saturation and diversity as mentioned in the earlier section.
1.5. What are the inclusion/exclusion criteria?	Inclusion criteria: The individuals who are have encountered Mycetoma in Wad Elneamir Village Sinnar, Sudan, and their caregivers, relatives, neighbors, and service providers. Exclusion criteria Visitors who are outside the study area.
1.6. Where will the project be carried out e.g. public place, in researcher's office, in private office at an organisation? Please list all research locations to be used.	The research will be conducted at different places, in the village where ethnography will be done, some of the interviews will be conducted in private office and some inside participants houses some of the health care professional will be interviewed in clinics and health care facilities

1.7. How will the results be analysed and by whom?	-Thematic framework analysis of qualitative data will be done through inductive processes. -Memo writing and/or recording will be carried out to describe details about the interview setting and interaction of respondent and interviewer that may not be captured in interview transcriptions. -the Ph.D. student will be for data collection, management and analysis under the direct supervision of the supervisors
>> Section 2. Informed Consent and Recruitment	
2.1. How will participants be approached and recruited? What specific mechanisms will be used e.g. social media, university circulation lists, intranets or any other external websites?	We will recruit participants through Mycetoma Research Center contacts and also through snowball sampling in which one patient will identify the other.
2.2. Please describe the process you will use to ensure your participants are freely giving fully informed consent to participate. In most instances this will include the provision of an Information Sheet and will require a Consent Form unless it is a purely self-completion questionnaire based study or there is justification for not doing so. (Please provide details if this is the case).	A Pre-consent information sheet will be provided to the potential respondents who will briefly describe the study, the intent, the benefits or risks or participating, voluntary nature of the study and also about the maintaining of the anonymity and keeping the information confidential. Informed consent will be obtained by the following process: The subject will be asked to review the study information sheet. The PhD student will meet with the subjects to discuss the form, to confirm the subject's understanding of the study, and to answer any questions the subject might have. Once the subject demonstrates understanding of the study and agrees to participate in the study, the consent will be signed. Because of the collective nature of the community in cases consent of the family members will also be needed. In such cases we will only interview a person when consent of the other family members is obtained.
2.3. Who will be taking informed consent? What training or experience have they received to do so?	The informed consent will be taken by Ph.D. student, who will get training in informed consent and ethical clearance
2.4. Participants should have the right to withdraw from the research at any time. Participants should also be able to withdraw their data if it is linked to them and should be told when this will no longer be possible (e.g. once it has been included in the final report). Please describe the exact arrangements for withdrawal from participation and withdrawal of data for your study.	The information sheet provided to the subject will clearly describe that the subject can withdraw at any point of time and also can refuse to answer any or all questions. If the participant decides to withdraw after giving the interview or data, he or she will be excluded from the final qualitative data set, and any information provided by the participant will not be used anywhere and deleted permanently.
2.5. Does the study involve participants who are particularly vulnerable, or unable to give informed consent, or in a dependent position (e.g. children (under 18), people with learning difficulties, over-researched groups or people in care facilities, including prisons) ?	No
2.6. Will a chaperone be required to be present during interviews? If so, please describe the chaperone arrangements.	No
2.7. Is Disclosure and Barring Service (DBS) clearance necessary for this project?	No

2.8. Will participants be asked to take part in the study without their consent or knowledge at the time (e.g. covert observation of people) or will deception of any sort be involved? Please refer to the British Psychological Society Code of Ethics and Conduct for further information.	No. The participants will not be included in the study if they do not give informed consent, no form of deception or disguise or covert observation will be used in this study.
2.9. Will participants be compensated for their time or be reimbursed for expenses? If so, how much?	No, they will not be compensated in any form for their time.
2.10. Could the study induce psychological stress or anxiety, or produce humiliation, or cause harm or negative consequences beyond the risks encountered in normal life?	No
2.11. Are alcoholic drinks, drugs, placebos or other substances (such as food substances or vitamins) to be administered to the study participants?	No
2.12. If the research involves physical intervention (e.g. imaging) have you considered the possibility that your investigations might uncover unexpected and possibly clinically relevant findings? How will this be managed?	As I'm a certified medical doctor, I may encounter or diagnose a case of Mycetoma. In that case, I will refer the patient to near Medical unit.
2.13. Can you think of anything else that might be potentially harmful to participants in this research?	No
2.14. Will you inform participants of the results of the research? Please give details of how you will inform participants or justify if not doing so.	We will use the result of this study to formulate a strategic plan for compacting Mycetoma, We will discuss with the community and community leaders, policymakers and Healthcare provides about the gaps, where we will mention that this has been developed based on research.
>> Section 3. Data Protection, Confidentiality and Records Management	
3.1. Does the project require access to personal records?	No
3.2. How will you ensure that the processing of personal information and personal identifiable information related to the study will be in full compliance with the General Data Protection Regulation (GDPR)?	The personal information will be collected from Sudanese respondents only. The personal data will be taken only after the participant understood the informed consent sheet that will be provided. - Only relevant personal data will be taken. - Steps will be taken to ensure the anonymization of the participant and the data is de-identifiable
3.3. If you are processing any personal information outside of the European Economic Area (EEA) you must explain how compliance with the DPA will be ensured.	The subjects of the study are Sudanese. The data will be processed in Sudan by the Sudanese researcher from the Mycetoma Research Center, Sudan. The researcher will be trained in the specific types of data collection in these kinds of research projects and are experienced in processing data fairly and lawfully.
3.4. Will you take steps to ensure the confidentiality of personal information?	Yes

3.5. Please provide details of anonymisation procedures and physical and technical security measures here.	Each of the participants will be given an unique identification number, they will not be identifiable by any means. The data will not be shared outside of the research team. All the qualitative data, transcripts and recordings will be kept under lock and key, and the digital records will not be shared with anyone outside of the team and will not be kept in the cloud server . If in the future this data is used for different purpose by personnel outside of the research team, de-identifiable data will be provided.
3.6. Will all personal information related to this study be retained and shared in a form that is fully anonymised?	Yes
3.7. If you answered "no" to the above question, you must ensure that these arrangements are detailed in the Information Sheet and that participant consent will be in place. If relevant, please outline arrangements here.	N/A
3.8. Will the Principal Investigator take full responsibility during the study, for ensuring appropriate storage and security of information (including research data, consent forms and administrative records) and, where appropriate, will the necessary arrangements be made in order to process copyright material lawfully?	Yes
3.9. If you answered "no" to the above question, please give further details.	N/A
3.10. Who will have access to personal information relating to this study?	Only the team involved in this research will be privy to the personal information pertaining to the participants. Anyone outside of the team will not be able to access that data
3.11. Data management responsibilities after the study: State how long study information including research data, consent forms and administrative records will be retained, in what format(s) and where the information will be kept. Please see the University's Research Data Management Policy.	The study information including research data, consent and administrative records will be kept for 2 years after the completion of the study. The administrative records will be kept in paper format, whereas the qualitative data and transcripts will be kept in digital format in a portable hard disk drive. The information will not be uploaded in any cloud server. The data will be accessible to other researchers once the proper data sharing policy of Mycetoma Resaerch Center has been followed
>> Section 4. Researcher(s) Safety and Wellbeing	
4.1. Does the project involve working with any substances and/or equipment which may be considered hazardous? (Please refer to the University's Control of Hazardous Substances Policy).	No
4.2. If yes, briefly state the substance(s) or equipment and briefly describe measures you will take to ensure the researchers safety and wellbeing.	N/A
4.3. Could the nature or subject of the research potentially have an emotionally disturbing impact on the researcher(s)?	Yes

4.4. If yes, briefly describe what measures will be taken to help the researcher(s) to manage this.	Because stigma and disablity is a sensitive situation or individuals with Mycetoma and their family members are emotionally vulnerable, we cannot rule out the fact that interviewing them may induce psychological distress and anxiety. We will take every step to ensure contextual sensitivity and make the interview as unintimidating as possible. If we notice any distress we will stop, and after some time ask the individual concerned whether s/he wishes to continue the interview.
4.5. Could the nature or subject of the research potentially expose the researcher(s) to threats of physical violence and/or verbal abuse?	No
4.6. If yes, briefly describe what measures will be taken to mitigate this.	N/A
4.7. Does the research involve any fieldwork - Overseas or in the UK?	Yes
4.8. If yes, where will the fieldwork take place? If the fieldwork will take place overseas please ensure that an OTSSRA form has been completed and the University of Sussex Insurance Manager has been consulted (insurance@sussex.ac.uk).	The field work will take place in Sudan. The data will be collected by the a researcher who are familiar with the setting.
4.9. Will any researchers be in a lone working situation?	No
4.10. If yes, briefly describe what measures will be taken to mitigate this.	N/A
4.11. Can you think of anything else that might be potentially harmful to the researcher(s) in this research?	No
>> Section 5. Other Ethical Clearances, Gatekeepers and Permissions	
5.1. Are any other ethical clearances or gatekeeper permissions required for access to participants or the research sites?	Yes
5.2. If yes, please give further details including the name and address of the organisation. If other ethical approval has already been received please attach evidence of approval, otherwise you will need to supply it when ready.	the ethical approval was allready obtained for Soba Center for Research and Audit, Soba Teaching hospital, University of Khartoum IRB No. 27122018
5.3. If the research involves storing and/or analysing human tissue or any human material will this be carried out under the University's HTA license?	No
5.4. Please also consider whether there are other ethical issues you should be covering here. Please also make reference to the professional code of conduct you intend to follow in your research.	N/A
>> Section 6. Conflicts of interest	
6.1. Do any researchers have any financial interests in this research or its outcomes or any relevant affiliations?	No
6.2. If yes, please give further details.	N/A

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CONSENT FORM

Title of Project: Socio-cultural and policy situation of Mycetoma and it is management in Sudan: A Critical Exploration

Name of Researcher: Mohamed Nasr Mohamed Ahmed Elsheikh

	Please initial box
I confirm that I have read and understood the information sheet dated 23.1.2019 for the study Socio-cultural and policy situation of Mycetoma and it is management in Sudan: A Critical Exploration. I have had the chance to read the information and ask questions about the study and am satisfied with the answers I have been given.	☐
I understand that my participation in this study is voluntary and that I am free to stop at any time, and I do not have to give a reason for doing so. I understand that if I ask to stop the study my medical care and legal rights will not be affected in any way.	☐
I understand that occasionally an external regulator or funding body may ask to look at the data for this study to check that it is being run correctly.	☐
I understand that my interview will be recorded and I agree to take part in the study	☐
I understand that our recorded conversation will be transcribed using anonymous identifiers and will not be linked to me or any other participant	☐
I understand that my research data will be stored for 10 years after the end of the study	☐
I understand that the date will only be shared with my research college Iam collaborating with to develop a mycetoma intervention	☐
I agree to take part in the above study.	☐

Name of Participant	Date	Signature

– –

- I have explained the information in this document and encouraged the participant to ask questions and provided adequate time to answer them.

Name of Researcher or Person Seeking Consent (If different from researcher)	Date	Signature

When completed: 1 copy for the participant; 1 copy for the researcher site file;

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PARTICIPANT INFORMATION SHEET

STUDY TITLE

Socio-cultural and policy situation of Mycetoma and its management in Sudan: Critical Exploration

INVITATION PARAGRAPH

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully

WHAT IS THE PURPOSE OF THE STUDY?

The aim of this study is to to understand how the individuals at different levels (National, Community and Individual) conceptualize and seek to manage Mycetoma in order to recommend sustainable strategies to prevent the disease.

WHY HAVE I BEEN INVITED TO PARTICIPATE?

You have been chosen because we think you have experience in relation to Mycetoma and its management.

DO I HAVE TO TAKE PART?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

WHAT WILL HAPPEN TO ME IF I TAKE PART?

If you participate in the study we will request you to take part either in an interview or a focus group discussion related to your experience of Mycetoma and its management. The interview will be conducted by one researcher and the focus group will be conducted by two researchers from Mycetoma Research Center/ Brighton and Sussex Medical School. The interview will be conducted in a place convenient to you. If any question is unclear to you or if you want to know why we are asking you these questions, you can ask us. If you are not willing to answer any particular question, it can be skipped. You have the full right to refrain from participation at any point. We will take all the care to make you comfortable but if you do not want to continue to talk or want to arrange another time we will do that accordingly. The interview will take about an hour.

WHAT ARE THE POSSIBLE DISADVANTAGES AND RISKS OF TAKING PART?

We don’t anticipate any possible disadvantage and risks of taking part in this study. However. If you feel anxiety we will stop the interview and ask you whether you wish to continue the interview.

WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

As I'm a certified medical doctor, I may encounter a case of Mycetoma. In that case, I will refer the patient to near Medical unit.

Based on the data we will suggest a community preventive plan and This will help in compacting the disease within the community. Your participation will ultimately help the community.

WILL WHAT I SAY IN THIS STUDY BE KEPT CONFIDENTIAL?

We will maintain absolute confidentiality. No personal data will be shared. If we use your views in our write up it will be done anonymously. The data will only be shared with my research colleague at Brighton and Sussex Medical School I am collaborating with to develop a mycetoma intervention.

WHAT SHOULD I DO IF I WANT TO TAKE PART?

You need to sign a consent form which we will supply you. Once you sign the form we will contact you for an interview at your convenient time and place.

WHAT WILL HAPPEN TO THE RESULTS OF THE RESEARCH STUDY?

Future results of this research will be shared among academics and non-academics in the form of journal articles, seminar and conference presentations. Results will also inform a future mycetoma intervention that will be co-developed with myself, my research colleague at Brighton and Sussex Medical School, and the community.

WHO IS ORGANISING AND FUNDING THE RESEARCH?

The research is led by Brighton Sussex Medical School, University of Sussex, UK. With coloration research will be conducted by Mycetoma Research Center, University of Khartoum, Sudan. The project is funded by the National Institute for Health and Research.

WHO HAS REVIEWED THE STUDY?

The research has been approved by the Brighton and Sussex Medical School Research Governance and Ethics Committee (RGEC) and University of Khartoum through Soba Center for Research and Audit, IRB No.20181227.

CONTACT FOR FURTHER INFORMATION

If you have any concerns regarding the conduct of this research project, you can contact DR. Mohamed Nasr Elsheikh, PhD Student BSMS and Research Assistant at MRC University of Khartoum, Sudan, Tel: +249 999219909, E-mail: almohamed1991@gmail.com

Or Dr. Shahudaz Zaman, Senior Lecturer, Global Health and Infection Department
Brighton and Sussex Medical School, University of Sussex, UKT: +44 (0)1273 877844, Email: s.zaman@bsms.ac.uk

Harm

The University of Brighton and Sussex have insurance in place to cover their legal liabilities in the unlikely event of harm should arise from this study.

THANK YOU

DATE: 17.11.2020

University of Brighton

Risk Assessment - 4674RA

Information valid as of 18/11/2020 03:56

Medium

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REVIEW REQUIRED

This assessment has been identified as being**OVERDUE** for for review..

General Details

Assessor	Mohamed Elsheikh
Assessment Date	06/11/2020
Assigned Reviewer	Mohamed Elsheikh
Next Review Date	11/11/2020

Operation Assessed	Possibility of encountering Coronavirus while on the Fieldwork

Associated with specific area

- Brighton and Sussex Medical School
- Brighton and Sussex Medical School
- All

Description of work area and/or activity assessed

This risk assessment focuses on my fieldwork to Sinner (South East Sudan).
I will be spending a few months in Sinner, carrying in-depth interviews and observation. The fieldwork is planned for the beginning of December 2020.

As my study is an ethnography, face to face interaction and observation is crucial. Moreover, alternative methods like using mobile phone or other virtual methods are not feasible because there is no electricity and mobile phone network. I have discussed this with my supervisor as there is no mobility restriction in Sudan, he suggested to go ahead with the field work after obtaining permission from BSMS and local administrative authority and with proper Covid-19 protection measure.

Overall Current Risk

Medium

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Likelihood	Severity				
	Minor	Moderate	Significant	Serious	Major
Rare	1	2	3	4	5
Unlikely	2	4	6	8	10
Possible	3	6	9	12	15
Likely	4	8	12	16	20
Almost Certain	5	10	15	20	25

Persons Affected

- Students
- Visitors

≡ Hazards

Current Rating	Hazard Information	Task Status
Medium 🟩🟩🟧⬛⬛	⚠ **Biological - COVID-19** Possibility of future transmission of coronavirus to me during the fieldwork	0 0 0
	Measures Currently in place to prevent risk of injury	
	- Sudan's situation is now expected after the government announces daily life return in early September 2020 and no new cases. - I have the ethical clearance from the local ethical committee to commence my fieldwork reference No. 27122018. - Furthermore, I will take the full protective measure as possible; I will put on the face-covering and ensure the social distancing, in addition to hand wash for 40 sec as Sudan federal ministry of health. I will also be living in a separate room to decrease the risk. - If I feel symptoms, I will follow the guidelines of Sudan FMOH. I will self-isolate myself for ten days, notify the university and the health authorities, and follow the guidelines. - At home, I will abide by the rules on visitors and social gatherings, ensuring that government guidelines are always followed. - Travelling: I already in Sudan (Khartoum), and travel is not restricted. - Accommodation: I will be living in a separate room to decrease the risk. - Equipment: I only have a personal digital tape recorder; it will not be shared and always cleaned. - I will have the appropriate first aid kit needed to respond to an emergency, such as gloves and including 2 x rubbish bags so that you can double bag tissues. before safe disposal - I'm not an at-risk individual to COVID 19.	

Potential Rating	Additional Controls Required
Medium 🟩🟩🟧⬛⬛	**No Remedial Actions Entered** If there are any reasonably practicable actions which can be taken to reduce the risk associated with this hazard please use the form above to enter them.

Current Rating	Hazard Information	Task Status
Medium 🟩🟩🟧⬛⬛	⚠ **Biological - COVID-19** Possibility of transmission coronavirus from the researcher (as a symptomless carrier) to the community	0 0 0
	Measures Currently in place to prevent risk of injury	
	- My fieldwork is not targeting the high-risk individuals '' elderly, children or pregnant women's.'' - I will take as maximum protective measures as possible; I will put on the face-covering and ensure the social distancing, in addition to hand wash for 40 sec as Sudan federal ministry of health. I will also be living in a separate room to decrease the risk.	

Potential Rating	Additional Controls Required
Medium 🟩🟩🟧⬛⬛	**No Remedial Actions Entered** If there are any reasonably practicable actions which can be taken to reduce the risk associated with this hazard please use the form above to enter them.

Related Files

بسم الله الرحمن الرحيم

University of Khartoum
Soba University Hospital

جامعة الخرطوم
مستشفى سوبا الجامعي

Date : 27 / 10 / 2020

Research Governance and Ethics Committee
Watson Building,
University of Brighton, Falmer
Brighton,
BN1 9PH

I'm writing to inform you that, regarding the Ethical application IRB No. 20181227, which entitles'' Sociocultural and policy situation of mycetoma and it is Management in Sudan: A critical exploration''—submitted by Dr. Mohamed Elsheikh. Soba Center for Research and Audit (SCAR) finds no COVID-19 restrictions and approve Dr. Mohamed to commence his fieldwork in Sinner.

Kind Regards

الإدارة

Dr. Ihab Abdelrahim
Director of Soba Center for Research and Audit

Tel: 00249155661403 – Fax: 00249155118813 Email:suh@uofk.edu

P.O Box: 8081 – Khartoum, Al- Amarat

ص. ب(8081) الخرطوم -العمارات

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BSMS Research Governance Ethics Committee

Certificate of Approval

Reference Number	ERA/BSMS9DHJ/9/1
Title Of Project	Socio-cultural and policy situation of Mycetoma and it is management in Sudan: A Critical Exploration (AMENDMENT)
Principal Investigator (PI):	Mohamed Elsheikh
Student	Mohamed Elsheikh
Collaborators	Dr Shahaduz Zaman (Supervisor); Dr Mei Trueba (Supervisor); Professor Amed Fahal (Supervisor).
Date Of Approval	24-Nov-2020
Approval Expiry Date	30-Sep-2021
RGEC Chair	Prof Valerie Jenkins
Name of Authorised Signatory	Caroline Brooks
Date	24-Nov-2020

The Brighton and Sussex Medical School Research Governance and Ethics Committee (RGEC) has assessed your application and granted Ethical and Research Governance Approval to proceed with the above named project.

Approval is granted on the following basis:

Amendment to commence fieldwork safely in Sudan during the COVID-19 pandemic.

Duration of Approval

Approval covers the period stated above. Research must commence within 12 months of the certificate start date; any delay beyond 12 months and this certificate of approval will lapse necessitating renewed review of the project.

Project Amendments

Any substantial changes or minor amendments to the project following issue of the certificate of approval should be submitted to the Research Governance and Ethics Committee for review and authorisation prior to implementation. Please submit your application for an amendment to the Committee (via rgec@bsms.ac.uk) using the Request for an Amendment Form.

Reporting Adverse and Unexpected Events

Any incidents occurring during the project's lifespan presenting ethical and safety implications must be reported immediately to the Chair of the Research Governance and Ethics Committee. In the event of an adverse (undesirable an unintended) and unexpected event occurring during the project, research must be stopped immediately and events reported to the Chair of the Research Governance and Ethics Committee within 24 hours of its occurrence.

Monitoring

The Medical School has a duty to ensure all its research is conducted in accordance with the University of Sussex's Code of Practice for Research and Research Governance and Ethical Review Framework. In order to ensure compliance auditing may be undertaken annually and /or periodic monitoring of a percentage of approved research studies. If your project is selected you will be given 4 weeks' notice to prepare all study documentation for inspection.

Notification of End of Study

Please notify the Research Governance and Ethics Committee once the study has completed. It is also your responsibility to inform the Committee in the event of early termination of the project or if the work is not completed.