

The London School of Economics and Political Science

Global Health, Local Realities:

Neglected diseases in northwestern Uganda

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Abstract

This thesis explores the everyday realities of neglected diseases among people living and working along the River Nile in Moyo and Adjumani Districts, northwestern Uganda. It is based on ethnographic-epidemiological fieldwork carried out over sixteen months during 2013 and 2014. The fieldwork included participant-observation, in-depth interviews and a parasitological survey with structured questionnaire. This thesis takes an interdisciplinary approach in studying global health, contributing to literature at the intersection between medicine and anthropology.

The neglected tropical diseases are a group of diverse diseases framed in global health around common socio-economic-political features, persisting in poverty. They affect neglected populations, neglected by public health policy. Current approaches to their management are largely a collection of technical, disease-focused programmes that disregard the politics of poverty. Contemporary debates surround the side-lining of social science literature, and the evidence behind the biomedically focussed disease control programmes.

Fisherfolk are said to be vulnerable to a number of these diseases. Diseases such as intestinal schistosomiasis (one of the neglected tropical diseases) persist in fishing areas despite a global public health programme. However, as this study demonstrates, in northwestern Uganda levels of schistosomiasis infection appear to have reduced. This study situates the success of the global health control programme within the local biosocial context. Furthermore, it shows that while one neglected tropical disease is controlled, other diseases persist and emerge. These other diseases explored in this research were Buruli ulcer and Hepatitis B, diseases that challenged the global health concept of neglected tropical diseases.

This thesis contributes methodologically to the growing interdisciplinary field of global health. It provides empirically-based biosocial evidence of the local realities of neglected diseases. In taking this approach, it argues that this concept is misleading. While it has illuminated particular problems in global health, the restrictive gaze disregards local public health concerns.

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1. GLOBAL HEALTH AND NEGLECTED TROPICAL DISEASES

“I have always had a certain dislike for general principles and abstract prescriptions. I think it is necessary to have an “empirical lantern” or a “visit with the patient” before being able to understand what is wrong with him.”
(Albert Hirschman, 1998, p.88¹)

The *neglected tropical diseases* are a group of diseases framed in global health around common social, economic and political features. These diseases, neglected by research and public health policy, affect poor, disenfranchised populations with little political voice; the ‘bottom billion’ (Feasey et al 2009; Hotez et al 2009; Payne & Fitchett, 2010). Given the impact of neglected diseases on global development, an increasing focus has been put onto their control and elimination by global health actors. Current approaches to their management instigated through global health actors are unfortunately largely a collection of technical, disease-focused programmes and these ‘one-size-fits-all’ programmes overlook the broader needs of the population. In so being, they are disregarding the social, economic and political dimensions² of health, illness and healing; disregarding the everyday reality of people who are vulnerable³ to many of these diseases (Parker and Allen, 2011; Parker et al 2012; Parker & Allen, 2013; Parker & Allen 2014).

This thesis explores these everyday realities. It is an empirical piece of work based on long-term ethnographic-epidemiological fieldwork in Moyo and Adjumani

¹ Quoted in Biehl and Petryna, Eds. (2013) p.14

² While I list these dimensions as separate entities, I also acknowledge that they are intrinsically linked. Just as within this thesis I attempt to understand the biological as intrinsically linked to these aspects.

³ I use the term vulnerability to reflect the societal-structural basis of health inequities, rather than individual basis of disease risk factors (Porter, Ogden & Pronyk, 1999:325)

Districts in northwestern Uganda. It is informed by my own background in medicine and medical anthropology, and by previous ethnographic fieldwork⁴ (Parker et al, 2012; Pearson, 2009). The initial focus was on intestinal schistosomiasis and other soil-transmitted helminths⁵ among people living and working along the River Nile; people who are arguably vulnerable to a number of the neglected tropical diseases, including these intestinal helminths, due to their adverse social, economic and political positioning.

The aims of this research were to explore the biosocial context of these diseases and the local realities of global health priorities. The research was shaped by taking an inductive interdisciplinary approach, and in doing so, I progressively started exploring other diseases that affected people along the river. These were Buruli ulcer and hepatitis B; diseases that challenged the global health framing of neglected tropical diseases.

Situating these diseases alongside each other allows us to contrast the distanced global health concept with local⁶ realities of neglect, health, illness and healthcare. The findings from this study uncover some key critical reflections on this. Schistosomiasis⁷ is a neglected tropical disease, yet it is arguably not so neglected now. A public health intervention has been implemented in the districts and it appears that levels of infection have reduced among adults. Yet Buruli ulcer⁸, which is described in global health as an emerging, neglected tropical disease, was neither emerging nor neglected for people along the river. While there is an absence of biomedicine, conditions understood as Buruli ulcer have been, and

⁴ In 2009, I carried out three months of ethnographic fieldwork in Moyo District for an MSc in medical anthropology at Brunel University.

⁵ Commonly called intestinal worms. They include the hookworms, *Ascaris* and *Taenia*.

⁶ By local, I do not mean 'traditional', rather everyday, lived realities and experiences.

⁷ Discussed in chapter four.

⁸ Discussed in chapter five.

continue to be, largely treated by local herbalists. On the other hand, hepatitis B⁹, which is not a neglected tropical disease, has emerged as a public health concern which, I suggest, is through the same features that have been attributed to neglected tropical diseases. These findings contrast 'on the ground' empirical findings with the framing of global health priorities.

These understandings only came about, as advised by Hirschman in the opening quote, by having an 'empirical lantern'; by visiting people declared to be affected by these diseases, those receiving the treatment through control programmes as prescribed by global health initiatives. Furthermore, these critical findings only became apparent through the fieldwork by taking an interdisciplinary, biosocial approach.

Farmer and colleagues have conceptualised this approach as fundamental to global health:

"All fields have myopias. The restrictive gaze of each discipline can illuminate certain global health problems; but only when they are taken together with a fully biosocial approach can we build, properly, the field of global health." (2013, p.9)

This thesis contributes to interdisciplinary research within global health and development between medicine and medical anthropology (Biehl and Petryna, 2013; Farmer et al, 2013; Harper, 2007; Kleinman, 1997). With the development of the field of global health, increasing attention is being paid to taking a biosocial approach to understanding global health issues. This study critically reflects on this, demonstrating what an interdisciplinary biosocial approach can look like with respect to neglected tropical diseases, the difficulties in this and the benefits for

⁹ Discussed in chapter six.

advancing knowledge in this field. This was not without tensions, methodologically and analytically. For while social science looks to critique and subvert received wisdom, biomedicine looks to find solutions to problems.

Being interdisciplinary, I situate biomedical knowledge and framing alongside other forms of knowledge (Hahn and Kleinman, 1983). While providing an anthropological analytical lens, the start and end points were not to critique biomedicine per se. Rather, they were to conduct an inductive analysis of the realities of neglect, disease and healthcare (in its many forms) for people vulnerable to these diseases, whichever direction this approach took. I attempt to re-socialize (Farmer et al, 2013) the global health concept, and in doing so I do not to overly objectify the findings from either a biomedical perspective, nor equally from an abstract theoretical perspective. This thesis is therefore an account of my attempt to navigate a middle empirical ground.

In doing so, this thesis attends to an empirical gap. There is sparse research on the biosocial context of neglected tropical diseases (Allen & Parker, 2011; Reidpath et al, 2011). Literature tends to focus on a specific neglected tropical disease either biologically (for example, research on schistosomiasis, Kabatereine et al 2003, 2004; Seto et al 2012; Rollinson et al 2013) or biosocially (for example *Taenia solium*, Bardosh et al 2014), or provides a theoretical contribution to the neglected tropical disease concept (Broadbent, 2011; Mantilla, 2011; Allotey et al, 2010). While looking at specific diseases, this thesis does not restrict itself to one disease or one discipline; rather it approaches the study of health, illness and healthcare through the lens of neglected tropical diseases as a concept. This thesis not only provides epidemiological evidence on the effect of ten years of mass drug administration for schistosomiasis and soil-transmitted helminths. It situates this evidence in the social context of schistosomiasis transmission and control. It resituates the

discussion on neglected tropical diseases within the life and livelihoods of those affected by these diseases and on the receiving end of the global public health control programmes. It therefore engages in other diseases and other forms of knowledge and healing practices beyond biomedical practices.

The thesis demonstrates on a number of levels the imperative of understanding the biosocial context of health, healing and illness, and therefore within this context the meanings of global health priorities. This is not only on local meanings of disease priorities but also meanings of public health interventions and research programmes (Geissler and Molyneux, 2011). I therefore critically reflect on the biosocial context of the research itself, of people's lives and livelihoods along the river in the two districts, and explore this not just from a biomedical perspective of diseases, but people's own understandings of affliction.

In discussing the three diseases in depth, the main argument of this thesis is that the framing of *neglected tropical diseases* is misleading. This paradigm has served to elicit a response in the field of global health and development; a response that has been influenced by the geopolitical landscape of this field. For a number of the diseases, public health programmes have been implemented targeting disease control, leaving aside the local realities of what it is that defines these diseases: poverty, neglect and marginalisation.

As Paul Farmer described for disciplines in the field of global health, so too the paradigm of neglected tropical diseases, although conceptualised as biosocial problems, is driven by a restrictive gaze. The myopia of disciplinary boundaries is illustrated by contemporary debates on neglected tropical diseases, discussed later in this introduction. However, the labelling of certain diseases as neglected tropical diseases, has not only served to illuminate them as global health problems, it has

also arguably led to a neglect of other health concerns. This, I suggest from my findings, is the case for hepatitis B. The emergence of hepatitis B as a public health concern in northwestern Uganda is a form of structural violence (Farmer, 1996; Farmer et al, 2004), arising through a structural silence;¹⁰ an outcome of the myopia in framing problems (and solutions) within global health.

How has this come about? What is the landscape of global health, and how has this influenced the conceptualisation of neglected tropical diseases and the solutions implemented to tackle these issues? Why is there so little engagement with the politics of poverty, neglect and marginalisation, the features that underline the characterisation of those affected by neglected tropical diseases?

This introduction proceeds by outlining the background to the field of global health which has developed from its predecessors, international health and tropical medicine. I discuss the predominance of biomedicine and the emergence of multiple actors influential in the landscape of global health. I then situate the neglected tropical disease paradigm within this landscape, showing how these diseases have been reframed to draw attention to them. However, while framed within the millennium development goals' mandates due to their socio-economic-political adversities, the solutions have largely been framed within a model of selective primary healthcare (Allotey et al 2010), influenced by biomedical technical frameworks and prominent disciplinary voices in global health. I draw on current 'deworming' debates and show that what this myopia leaves aside are the realities of neglected tropical diseases for those affected. This thesis begins to reset this imbalance of voices by situating the neglected tropical diseases concept within the everyday reality of people vulnerable to them. In this thesis I studied people's lives

¹⁰ In approaching hepatitis B through the lens of neglected tropical diseases, I do not substantiate this hypothesis further through narratives of global health actors and institutions.

and livelihoods along the River Nile in northwestern Uganda. I therefore outline relevant literature on fisherfolk and health, which largely focusses on The Great Lakes in East Africa and HIV/AIDS. I conclude the introduction by outlining the background to the research and the thesis structure.

GLOBAL HEALTH

The developing field of global health has been shaped by its historical roots and the many contemporary actors involved. This has influenced both how problems in global health are regarded, and how solutions are devised.

Global health has established itself as common nomenclature over the past ten to fifteen years, with an increasing use of the term in scientific publications in medicine, social science and other academic fields¹¹. It has taken over from “international health” as the preferred term to describe public health matters beyond national concerns of developed countries. Despite the increase in its use, the meaning of global health is largely not clarified (Fassin, 2012), although it is commonly agreed that it “implies consideration of the health needs of the people of the whole planet above the concerns of particular nations” (Brown, Cueto and Fee, 2006, p.62). Brown, Cueto and Fee (2006) link the proliferation of the term to survival strategies of the World Health Organisation following the growing influence of the World Bank in population health through the 1970s and 1980s, and a crisis of funding in the 1990s. Beyond this, the field of global health has surfaced within broader geopolitical changes that can be traced back further, along with the establishment of biomedicine.

The nineteenth and twentieth centuries saw an expansion of scientific reasoning, theories of evolution, medicine and germ theory. Alongside this, Lock and Nguyen

¹¹ Demonstrated through a Scopus search for the term “global health” by year and by discipline.

(2010) loosely distinguish four phases in the rise of biomedicine in global health. Pre-1920s, biomedicine was intimately linked with imperialism and empire building which developed into colonial endeavours in the 1920s to 1960s. With independence from colonialists, in the 1960s to 1980s it was linked with nationalism and nation building. From the 1980s there has been a rise in non-governmental organisations' involvement in global health and development (p.148).

While health has been a concern of imperialism across many empires, the roots of global health can be located in particular in the period of colonial medicine (reviewed by Greene et al, 2013). Whereas initially health and sickness of Europeans in Africa, Asia and America were a primary concern for colonisers, at the end of the nineteenth and early twentieth century overlapping roles of medicine and "civilisation" developed, through colonisation and the religious conversion by missionary expeditions (discussed pp.36-41). Greene et al state that this period "illustrates the use of "the tropics" as a laboratory and a source of test subjects for medical and public health research and practice" (p.37). With biomedical advances (the development of antibiotics, vaccinations, microscopy and the identification of micro-organisms as a cause of disease) there was a focus on managing outbreaks of disease or epidemics such as malaria, yellow fever and sleeping sickness. This provided evidence of the efficacy of biomedicine and "opened a door for biomedicine to be used as an ideological tool, a way of winning "hearts and minds" and showing what colonial authorities believed to be the beneficial effects of colonialism" (Lock and Nguyen, 2010 p.154). It was also a form of biopower (Foucault); as Lyons argues, sleeping sickness legislation in the Belgian Congo was an attempt at 'social engineering' (1985, p.70).

During this time the field of *tropical medicine* developed, with the Liverpool School of Tropical Medicine established in 1898 by Sir Alfred Jones a ship-owner with links to West and South Africa (Power, 1999), and the London School of Hygiene and Tropical Medicine by Sir Patrick Manson in 1899 (Cook, 1990). Alongside this, concerns developed over *hygiene* practices, the root of what is now termed *public health*. While global health represents transnational linkages and globalisation, as Greene et al (2013) state, “The history of tropical medicine helps explain why in rich countries the phrase “global health” connotes disease of “elsewhere”-problems affecting an othered “them” rather than an inclusive “us”” (p.42). It also illustrates the origins of the focus on disease, germs and vectors.

In the first half of the twentieth century, the US Rockefeller Foundation began focusing on *international health* through its funding of programmes to control infectious diseases in American states. Other institutions for international health emerged through to the middle of the century: the Pan American Health Organisation (PAHO), and following World War Two the United Nations agencies including the World Health Organisation. In this post-war, Cold War period which also saw the independence of many colonies, the concerns of international health were largely conceptualised within nation states, and included welfare and development. During this time, the Global Malaria Eradication Programme, a top-down widespread campaign, was implemented by the WHO in the 1950s. It was arguably over-ambitious and failed to achieve eradication in many countries outside the United States and Europe (Nájero et al 2011). As Greene et al (2013) note, this was in contrast to the subsequent smallpox vaccination campaign which achieved eradication by the end of the 1970s. The Global Malaria Eradication Programme illustrated the difficulties in relying on top-down interventions, but the small pox

campaign served as evidence of success, reinforcing this approach in international health.

This set the scene for debates that stem from the latter decades of the twentieth century and continue today. In the late 1970s the ideals of the primary health care model were set out in the Alma Ata declaration of 1978, addressing social and economic dimensions of population health. The declaration of “health for all by the year 2000” through community-based primary health care quickly transformed into what was meant to be an interim strategy (Basilico et al 2013). In less than a year, a conference was held on Selective Primary Health Care, a way of fixing and financing some of the health concerns established through the Alma Ata declaration (ibid.). The practical, technical fixes of Selective Primary Health Care were exemplified through early initiatives such as GOBI (Growth monitoring, Oral rehydration, Breastfeeding, Immunizations). These were based on specific interventions that could have measurable effects, providing a means to monitor and evaluate their implementation (ibid.). In the face of neoliberalism, the debt crisis in the 1980s¹² and structural adjustment policies, during which time HIV/AIDS emerged as a significant epidemic, the shift away from the comprehensive primary health care model was cemented.

Given this background, the transition from international health to global health in the twenty-first century occurred within increasing globalisation, awareness of inequities that arise from this, and with this an increasing human rights based approach to health and healthcare (e.g. Farmer, 1999). This transition has also seen a broadening of the scope of actors involved in population health. Beyond national

¹² Basilico et al argue that the response to the debt crisis, featured a prominence of “*economic knowledge* (interest rates, public spending, inflation), supplanting other types of knowledge (political, medical, ecological, local)” (p.93).

governments and intergovernmental institutions such as the United Nations organisations including the WHO, there has been a rise in public-private organisations, philanthropists and non-governmental organisations.

As an example, The Bill and Melinda Gates Foundation is currently one of the biggest grant-givers for many global health initiatives. McCoy et al (2009) analysed the scope of the Gates Foundation in global health. With grants that vary from a few thousand US dollars to hundreds of millions of US dollars, they fund global health partnerships; non-governmental and non-profit organisations; universities, particularly in the US and the UK; and inter-governmental organisations including the WHO, the International Bank for Reconstruction and Development, and UNICEF. On the other hand, they don't directly finance governments and for-profit organisations. The majority of funding goes to large supranational organisations and global health partnerships with recipients in high-income countries, mainly the US but also the UK, Europe and Australia. One consequence is that to a larger or lesser degree, money, power and resources are held outside the direct remit of the states which are the eventual recipients. Secondly, through this large network, McCoy et al indicate, "All the key contributors to global health have an association with the Gates Foundation through some sort of funding arrangement" (p.1650).

The Gates Foundation does not only give grants, but has representatives on governing structures for a number of global health partnerships; being a member of the H8 global health leaders (along with the WHO, WB, GAVI Alliance, Global Fund, UNICEF, UNFPA, and UNAIDS), and involved in setting G8 health agendas (ibid.). While the importance of the funding cannot be denied, the influence and biases that enter global health agendas from this has been questioned (Okie 2006). McCoy et al (2009) suggested that "the Gates Foundation is keen to promote the growth of private health-care providers in low-income and middle-income

countries” (p.1651) and likewise prioritise technological interventions. However, we have seen that this technological bias also has roots in the historical underpinnings of tropical medicine and international health, alongside this contemporary picture of global health funding and influence.

Transitioning into the twenty-first century, the current remit of global health is explicitly linked with social and economic development. Many of the millennium development goals and their targets address issues of public health and vice versa. More recently, alongside an increasing arena of vertical, technical disease-specific programmes, there has been a resurgence of the primary health care model with the 2008 World Health Report, “Primary Health Care: Now More Than Ever”. Since 2012, the Gates Foundation has also been promoting integration and improving health system delivery and primary health care systems as part of its global health and development programme, yet still promoting the delivery of technical solutions¹³.

While there has been an increase in these top-down approaches, there has also been an increasing concern to bring in the perspective of the people that the institutions of global health aim to alleviate the suffering of (Biehl and Petryna, 2013). This is also not a new phenomenon, with medical anthropologists and physician-anthropologists advancing the need for an interdisciplinary or biosocial approach to understanding health concerns wherever they occur (for example, Kleinman, 1995; Helman, 2007).

Returning then to the emergence of the field of global health, it has opened opportunity for new ways of framing or re-framing health concerns. Farmer et al describe global health as “not yet a discipline but rather a collection of problems”

¹³ <http://www.gatesfoundation.org/What-We-Do/Global-Development/Integrated-Delivery>

(2013, p.2), problems that stem from inequities in both the distribution of, and means to alleviate, risk and suffering. They therefore propose that this necessitates an interdisciplinary approach to understanding these problems alongside the biomedical, whether through historical, economic or political economy analyses. In this regard, they frame the field of global health within a rights discourse, using this to advance a way of understanding and addressing the problems of inequity in health beyond biomedicine. Fassin (2012) notes that the rise of the term global health is not for describing new problems but rather he uses Foucault's term "new 'problematizations'", as "new ways of describing and interpreting the world – and therefore of transforming it" (p.113).

With this backdrop of globalisation and the problematization of global health, a group of diseases have been advanced as the *neglected tropical diseases*. This paradigm has largely come about by the re-framing of a number of individual diseases in competition with more visible global health 'threats'; threats of global pandemics, HIV, SARS and swine flu for instance, threats that are framed within a competing global health narrative of 'biosecurity' (Leach and Tadros, 2014). Neglected tropical diseases on the other hand, are threats to socio-economic development and pose little risk of epidemics outside of tropical countries.

NEGLECTED TROPICAL DISEASES

Within this landscape of global health, neglected tropical diseases have been conceptualised as diseases of poverty, yet many of the solutions for these diseases of poverty are delivered through disease-focused programmes. How has the reconceptualization of neglected tropical diseases come about? How has this influenced the global health response to these diseases, as individual diseases and as a group of diverse diseases?

Neglected tropical diseases, associated with poverty¹⁴, were largely defined by the people they affect:

“... often the poorest populations, living in remote, rural areas, urban slums or conflict zones. Neglected tropical diseases persist under conditions of poverty and are concentrated almost exclusively in impoverished populations in the developing world.

Lacking a strong political voice, people affected by these tropical diseases have a low profile and status in public health priorities.”¹⁵

The concept of neglect was not specifically defined (Broadbent 2011, Mantilla 2011) but rather, as illustrated in the quote, established in a number of ways. The diseases affected neglected populations. The diseases had been neglected by public health institutions. Furthermore, they had been neglected by research and development: with little market incentive, they were a low priority for the development of new pharmaceuticals.

Despite this, Molyneux et al (2005) argued, there was potential for controlling, preventing and even eliminating many of these diseases. This led to claims that tackling neglected tropical diseases would rescue “the bottom billion” (Hotez 2009), and the development of vaccines would act as “anti-poverty vaccines” (Hotez and Ferris, 2006).

The diseases themselves are in fact diverse (table 1). Biologically, they are caused by a variety of pathogens and transmitted in a variety of ways with many involving

¹⁴ The diseases reinforce poverty through their effect on individuals and households, and poverty increases people’s vulnerability and exposure to these diseases and morbidity from these diseases, for example through limited access to healthcare.

¹⁵ An answer to a question posed on the WHO website, ‘why are some tropical diseases called “neglected”?’ <http://www.who.int/features/qa/58/en/>

intermediate hosts (such as snails in schistosomiasis), or vectors (such as mosquitoes in lymphatic filariasis and black flies in river blindness). They have diverse effects on the body. Some cause insipid symptoms that don't emerge until months or years after infection. Some cause visible and disfiguring lesions (such as in leprosy or Buruli ulcer), while others (such as rabies) can be quickly fatal. Preventative, treatment and control measures also vary.

Protozoa	Helminth
Chagas disease	Cysticercosis/Taeniasis
Human African trypanosomiasis (sleeping sickness)	Dracunculiasis (guinea-worm disease)
Leishmaniasis	Echinococcosis
	Foodborne trematodiasis
Bacteria	Lymphatic filariasis (elephantiasis)
Buruli ulcer	Onchocerciasis (river blindness)
Leprosy (Hansen disease)	Schistosomiasis (bilharzia)
Trachoma	Soil-transmitted helminthiasis
Yaws	
Virus	
Dengue and Chikungunya	
Rabies	

TABLE 1: WHO LIST OF NEGLECTED TROPICAL DISEASES¹⁶

The local environment plays a determining role. Vulnerability to disease is affected by people's contact with environments that harbour the pathogen, vector or intermediate host. For instance, outbreaks of sleeping sickness have been associated with conflicts and more recently with cattle markets in Uganda (Févre et al 2001; Hutchinson et al, 2003). Many of the intestinal helminths are associated with faecal contamination of food, water and the environment due to poor sanitation and unsafe water sources (Gryseels et al 2006). Emergence or re-emergence of many of the diseases are also linked to environmental changes, in

¹⁶ Taken from http://www.who.int/neglected_diseases/diseases/en/

particular man-made changes such as deforestation and water projects like irrigation systems¹⁷ (Patz et al 2000). This vulnerability is therefore largely determined by structural factors, rather than solely climatic factors, as the term ‘tropical’ suggests.

However, the diseases are co-endemic across many tropical areas, including South America, India, China and Africa. In general, there are high rates of co-endemicity in sub-Saharan Africa (Molyneux et al 2005) and many countries on the continent have the greatest burden of disease (Hotez and Kamati, 2009).

At the time of writing, the World Health Organisation (WHO) NTD department recognises seventeen ‘neglected tropical diseases’. In addition, the WHO NTD department supports seven other ‘neglected conditions’¹⁸ that do not come under other WHO programmes. Additional health concerns are often lobbied as ‘neglected’ in global health, such as mental health (Patel et al 2008). Even within the group, some diseases are advocated to be ‘the most neglected of the neglected tropical diseases’ (Olsen et al, 2009, discussing strongyloides) or ‘neglected, neglected tropical diseases’ (Budke et al, 2009, discussing zoonotic larval cestode infections).

While there has been this recent interest in global health, many of these neglected tropical diseases have been around for millennia. For instance, Egyptian mummies have been found to have signs of schistosomiasis (Kloos and David, 2002).

Furthermore, many of the diseases have not always been a distant concern of western governments. Sleeping sickness in the late 19th and 20th centuries was

¹⁷ For example, schistosomiasis.

¹⁸ Chronic suppurative otitis media, mycetoma, nodding syndrome, podoconiosis, ectoparasites, snakebite and strongyloides.

central to much public health policy in parts of Africa under colonialism¹⁹. These diseases have also been prevalent and subsequently controlled in now developed states. In the early twentieth century, hookworm was prevalent in the southern and south-eastern states of the United States²⁰ and treatment programmes were initiated through the Rockefeller Sanitary Commission to reduce the social and economic burden of the disease (Brown, 1976). Current responses echo this.

Furthermore, despite the areas of social, economic and political neglect, with successful lobbying, neglected tropical diseases have gained increasing interest among research institutes, pharmaceutical companies, donors, governments and non-governmental organisations. While these diseases were initially under the WHO group of 'other communicable diseases', in 2005 the WHO coined the term 'neglected tropical diseases'. In 2007 a WHO meeting was held of global partners on neglected tropical diseases, which included Member States, UN agencies, the World Bank, philanthropic foundations, universities, pharmaceutical companies, international non-governmental organisations and other institutions. There is now a WHO department for the control of neglected tropical diseases, a Global Network for Neglected Tropical Disease, research institutes (such as the Centre for Neglected Tropical Diseases at the Liverpool School of Tropical Medicine) and partnerships, and a dedicated peer-reviewed journal (the open access PLoS NTDs).

¹⁹ Much of the symbolism in Joseph Conrad's *Heart of Darkness* can be seen as a reference to sleeping sickness, 'the colonial's disease' as it was known; or vice versa, the disease was seen as a metaphor for colonialism (Dempsey, 2013). Early 20th century sleeping sickness policy included clearing tsetse fly habitats, villages were uprooted and moved, 'cordon sanitaires' were set up to control the spread of disease, also, Lyons argues, a means of controlling populations (Lyons 1985).

²⁰ Known as the 'germ of laziness' because of the anaemia it caused, hookworm was associated with decreased productivity of the poor agricultural or industrial workers. It was controlled in these states largely through improvements in living conditions, particularly sanitation, in the early twentieth century (Brown, 1976).

This largely came about through millenium development goal 6: to combat HIV/AIDS, malaria and the open ended category of 'other' diseases. Only tuberculosis was named as one of these 'other' diseases. Neglected tropical diseases, opposed to the big three of HIV, malaria and tuberculosis, were argued to have a significant impact in rural and impoverished urban areas in low income countries (Hotez, 2009). This impact was measured in terms of the significant morbidity and mortality when combined as a group, and the socio-economic impacts of these diseases.

The measure used was Disability Adjusted Life Years (DALYs), a composite measure of disability and death related to a specific cause (Merson et al, 2012). As individual diseases the DALYs for neglected tropical diseases varied and were less significant. Hotez and Kamath (2009) however, illustrated that in aggregate, they are estimated to follow HIV and malaria in terms of their DALYs. They demonstrated that the disease burden in sub-Saharan Africa was 64 million for HIV/AIDS, 40.9 million for malaria, 8.6 to 21.2 million for neglected tropical diseases, 5.4 to 18.3 million for helminth infections and 9.3 million for tuberculosis (ibid. table 3). This visualised the neglected tropical diseases as a significant global health concern. However, many have critiqued the use of DALYs as an indicator, not least because of the social values of life that are made within the estimates (Cohen, 2000; also discussed in Merson et al, 2012). Vital statistics are used to build up the model of Global Burden of Disease, yet in areas where neglected tropical diseases largely occur, rural areas in low-income countries with already fragile health systems, there are limitations in the use of health registers (Cohen, 2000). Further, these statistics do not measure the other aspects of these diseases, the social and economic impacts (ibid.).

Along with this illustration of the public health significance of these diseases as a group compared to HIV, malaria and tuberculosis, a second factor put forward was the cost-effectiveness of combination treatment for a number of these diseases. The rationale was that for a group of the diseases (including intestinal helminths, river blindness and lymphatic filariasis) the comparative cost of treating a patient per year, was much smaller than treating either of the three of malaria, HIV/AIDS and tuberculosis (Molyneux, Hotez and Fenwick, 2005). Molyneux et al demonstrated that the cost of a *Rapid Impact Package* for integrated control of seven neglected tropical diseases with four drugs was at around 0.40 US cents per patient per year, compared to the nearly 1000 US dollars it cost to treat a patient per year for HIV/AIDS (ibid. p.1067). Therefore, where safe, effective and cost-effective treatment is available in tablet form, preventive chemotherapy is delivered. Bruun and Aagaard-Hansen (2008) argue that this strategy of mass drug administration is largely based on this availability of low-cost drugs.

Therefore, these diseases came to global health attention through being framed within the millennium development goals and pitched against the big three of HIV, malaria and tuberculosis (Hotez et al, 2007). The imagery used facilitated a response: such as the *scourge* of Chagas' disease in America (Hotez, 2012), a term of suffering, historically derived from punishment; or the need for a response in *rescuing the bottom billion* (Hotez et al, 2009). It was then not only the potential fatal consequences of disease, such as liver disease in schistosomiasis, that needed to be addressed by a global public health campaign, but the cumulative, insidious effects of chronic morbidity, disability, anaemia, poor school performance and educational attainment. Only when combined together and in relation to social economic concerns, could these diseases be seen as a global health and development problem. In effect, grouping these diseases created a sum that was

equal to more than its parts. Situating the diseases together and within a new framework resulted in drawing global attention to them. Framing these diseases as neglected tropical diseases provided a moral imperative to respond (Parker & Allen 2014). In this case however, the response has been predominantly through the provision of biomedical technical fixes; a response that has both historical roots and contemporary biases in global health.

In contrast, as Allotey et al (2010) observe, the structural factors, such as poverty, safe water and sanitation that underlie these diseases have gained less attention in policy, being implemented on a small scale without the same advocacy behind them²¹. The initial powerful voices came from within biomedical fields, and much of the powerful response has come from philanthropists and pharmaceutical companies (Allen and Parker, 2011). The management of these diseases has largely been effected through public-private partnerships – an illustrative component of the landscape of contemporary global health.

This landscape includes pharmaceuticals and funding. An initially cited problem was the financing of research, control programmes, and pharmaceutical development. In particular, there had been very little development of new drugs for many of the diseases. For instance, praziquantel for schistosomiasis was initially a veterinary drug before being licensed for human use²². Broadbent (2011²³)

²¹ There is one near 'success' story in terms of the potential for eradication of a neglected tropical disease in more recent years. At the time of writing, guinea worm has been eradicated except in four countries in Africa (Chad, Ethiopia, Mali and South Sudan with nearly 80% of the cases being in South Sudan). The mainstay public health interventions revolved around water (improving water supplies, and providing or encouraging filtration of drinking water) and treatment of the wound caused by the worm breaking through the skin. While there is a lack of biomedical treatment, the public health response still included biomedical and technical fixes: chemically treating drinking water sources and distributing worm filters (see Moran-Thomas, 2013). The approaches to control are still predominated by select interventions.

²² <https://web.stanford.edu/class/humbio103/ParaSites2006/Praziquantel/history.html>

argues that this focus on neglect of pharmaceutical Research and Development (R&D) is misleading as this is not necessarily the limiting factor affecting the distribution or control of the diseases. However, whether pharmaceutical R&D is the limiting factor or not, pharmaceuticals have been the predominant approach for controlling a number of these diseases. Private funding has been a crucial element in this. McCoy et al (2009) estimated that the Gates Foundation contributed about a fifth of all funding for pharmaceutical R&D for neglected diseases. In addition, some pharmaceutical companies now donate the drugs for some of the neglected tropical diseases free of charge.

This arguably has had an influence on the global health strategies to control neglected tropical diseases, as onchocerciasis control in African countries demonstrates (Liese et al 2010). Described by Liese and colleagues, the first and now longest running initiative for one of the neglected tropical diseases was the Onchocerciasis Control Programme (OCP), conceived in 1968 and rolled out in 1974 with co-sponsorship by the WHO and other UN agencies. However, in the late 1970s and 1980s momentum dwindled, firstly with a focus on primary health care

²³ Broadbent (2011) argues that the issue is not in the research and development of new pharmaceuticals for the diseases, but in “investing in profitable ways to reduce their burden”. He uses the example of yaws where penicillin has been effective in reducing the burden of disease and even eradicating it in many areas and later concludes that “It cannot be assumed that commercial vigor would enable some new drug to overcome whatever barriers currently exist to the distribution of penicillin” (p.56). Broadbent uses an example where there is effective treatment, although concerns over resistance and the reliance on one drug exist. However, in the case of sleeping sickness, discussed elsewhere in this chapter, the current treatment, while potentially effective, is not ideal for all cases of sleeping sickness. The main point to make here is that pharmaceutical R&D may be an issue for some diseases grouped under neglected tropical diseases but it is not necessarily the limiting factor for tackling the issues of controlling these diseases. In fact, for yaws there is relatively simple and tolerable treatment. The current recommendation for first line treatment and control of yaws is a one-off dose of azithromycin (another antibiotic), but, as stated on the WHO website (<http://who.in/yaws/epidemiology/en>), the difficulty in assessing control and reduced burden of disease is that the extent of the disease is not known. While yaws was eradicated in some areas during campaigns in the twentieth century through the administration of penicillin, and is treatable with antibiotics, it remains endemic in many countries.

and the social and economic determinants of health, and secondly with the recognition of HIV/AIDS. The OCP initially involved larviciding along rivers in eleven West African countries. In 1987 the pharmaceutical company Merck, provided Ivermectin, the drug for treating onchocerciasis, free of charge 'for as long as needed', shifting the control focus to mass drug administration. The initial programme concluded in 2002. In 1995 the African Programme for Onchocerciasis Control (APOC) followed a similar collaboration, expanding to the remaining nineteen endemic countries. This relied entirely on mass drug administration and, governed by a memorandum of understanding, it was implemented through the national state.

Currently, the strategies advocated by the WHO to control neglected tropical diseases include similar preventive chemotherapy, enhanced case management²⁴, expanding treatment access, integrated vector control²⁵ and zoonosis control²⁶. Some of the neglected tropical diseases require treatment strategies, such as active or passive surveillance for sleeping sickness. The treatment for sleeping sickness is provided through a public-private partnership between the WHO and pharmaceutical companies and directed through MSF Logistics (Butler, 2003). The Drugs for Neglected Tropical Diseases initiative (DNDi) was set up as a not-for-profit organisation for the research and development of new drugs, including for sleeping sickness for which some of the drugs used to treat it are extremely toxic (Pécoul

²⁴ Some diseases require active case detection and treatment, for instance, sleeping sickness, which may have a long latent period with no symptoms, or non-specific symptoms. The treatment is also extremely toxic – melarsoprol, which is used to treat second stage *T. rhodesiense* form of sleeping sickness, is derived from arsenic.

²⁵ Many of the diseases are vector borne, or have intermediate hosts. For sleeping sickness, which requires active case management, a broader strategy to reduce the cases is to manage the vector, the tsetse fly.

²⁶ That is, coordinating with veterinary public health for diseases that have animal hosts.

2004). However, the primary strategy for at least four of the diseases remains preventive chemotherapy.

A number of diseases have therefore been re-framed as ‘neglected tropical diseases’. I have shown here how this has coincided with a shift towards public-private partnerships and philanthropists in global health agendas, occurring alongside a shift from ‘international health’ to ‘global health’. Neglected tropical diseases were framed, not about a common biological basis nor as a biosecurity threat, but about a common socio-economic basis, with the outcomes of controlling these diseases in line with the millennium development goals. Health has been defined as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” by the WHO since 1948²⁷. Yet, while the stated aim of neglected tropical disease interventions is to alleviate suffering and improve socio-economic outcomes, this is largely dealt with through treating or controlling disease. I have demonstrated how this has been influenced by the geopolitical landscape of global health with the powerful voices within this field biased towards biomedicine, pharmaceuticals and technical fixes.

What has been the effect of these restrictive gazes on the broader concerns of neglected tropical diseases? In the following section I show how this has shaped contemporary debates around neglected tropical diseases surrounding the evidence for one of the control programmes. Likewise, these debates have largely been situated within disciplinary boundaries, despite the inherently biosocial nature of the diseases. Furthermore, counterpoint evidence has been set aside, including both biomedical and anthropological evidence.

²⁷ Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948.

EVIDENCE AND THE CONTROL OF NEGLECTED TROPICAL DISEASES

Schistosomiasis, soil-transmitted helminths, lymphatic filariasis and onchocerciasis are managed through an integrated programme delivering three, free drugs (albendazole donated by GlaxoSmithKline, ivermectin donated by Merck & Co., and praziquantel). These drugs are administered to school children in endemic areas and adults at high risk. The intervention, called mass drug administration, involves distributing these drugs to populations through a network of voluntary, unpaid, community drug distributors (Hotez, 2009). This approach and the evidence behind it have been widely contested across a number of disciplines in global health.

The term neglected tropical diseases, the first WHO report (2010) stated, represented a shift away from strategies focused on individual diseases, to strategies focused on the integrated control of these diseases. Yet, for the diseases named above, integrated control involved combining the delivery of drugs as vertical health programmes, integrating treatment as a form of control, not integration across sectors (healthcare, water and sanitation for example) or integration within a primary healthcare system. It has been argued therefore that the control programmes are effectively working as a form of selective primary healthcare (Allotey et al, 2010; Allen & Parker, 2011). In doing so, they revisit previous paradigms in international and global health. While the concept of neglected tropical diseases encompassed broader social, economic and political aspects of health and 'health for all', the strategy quickly became the implementation of technical fixes, of "magic bullets" (Allotey et al, 2010).

Research addressing the social and cultural aspects of the diseases and programmes has illustrated pitfalls of these narrow approaches to health and disease. One of the limitations in a biomedical approach is the exclusion of the

local context in 'one size fits all' policies. Much of the research on local responses to neglected tropical diseases and programmes implemented to control them has focused on lymphatic filariasis and schistosomiasis (Parker et al, 2008; Parker and Allen, 2011; Allen and Parker, 2011). This research explored biomedical and local understandings of health and illness, and social responses to the roll out of mass drug administration aimed at controlling these diseases.

One finding was that local understandings of the programme differ from its aims. Integrated control included the integration of treatment and control. For the diseases managed through mass drug administration, this meant that treating populations irrespective of disease status was a form of controlling the diseases by reducing parasite burden in those infected and therefore with the aim of reducing transmission (Hotez et al, 2006). However, this has not been without confusion, as Allen and Parker found with lymphatic filariasis in Tanzania (2011). The symptoms of lymphatic filariasis include swollen legs and swollen testicles in men (due to a blocked lymphatic system). Administering ivermectin and albendazole does not reverse these changes, leading some people to question the efficacy and true purpose of the drug distribution programme (ibid.). The public health aims of the programme (control) did not meet the expectations of those receiving it (treatment).

Furthermore, Allen and Parker's work on neglected tropical diseases in Uganda and Tanzania demonstrated that mass drug administration programmes did not run as smoothly as was often alluded to in the biomedical literature. This work became controversial and elicited a fierce response from biomedical scientists behind the programmes (Allen and Parker 2011; Molyneux and Malacela 2011; Allen and Parker 2012; Molyneux et al 2012). In a paper titled 'De-politicizing NTDs', Parker and Allen (2014) suggested that the growth of mass drug administration, without

relating to local political, historical, social, and economic circumstances, was analogous to what James Ferguson (1990) has called anti-politics in development programs. However, they take the argument further suggesting that cognitive dissonance, enabling both biological and social evidence that contradicts the objectives and norms of the programmes to be put aside, is strategically employed. They argue that in doing this, it is used as a tool to secure grants and promote institutional interests, with these responses being reinforced by the financial incentives for global health programs and their emphasis on impacts and targets.

It is not only other forms of evidence that have been put aside. With the rise of evidence-based medicine (EBM), the biomedical gold standard method for evidence in global health is the randomised controlled-trial, sidelining other forms of evidence and knowledge (Lock and Nguyen 2010, p.188). Yet, given that this is the gold standard, even this has been put aside within biomedicine (Hotez, Mistry and Fenwick 2012²⁸). This has led members of the Cochrane Infectious Diseases Group to question the neglect of evidence-based policy among neglected tropical disease academics (Nagpal, Sinclair & Garner, 2013).

Within biomedicine, questions have been raised on the limited epidemiological evidence behind the programmes of mass drug administration for intestinal helminths (Taylor-Robinson et al 2012; Garner 2012). In particular, there are doubts on the claims that they improve socio-economic achievements including school attendance and performance. These debates have made headline news in popular press. On 5th August 2015, The Guardian newspaper published a piece

²⁸ Blog post: Deworming should remain an essential cornerstone for NTD control, posted 18th July 2012, <http://blogs.plos.org/speakingofmedicine/2012/07/18/should-deworming-policies-in-the-developing-world-be-reconsidered/>

titled “Explainer: Where were you in the #wormwars?”²⁹ It was commenting on recent twitter and blog feeds sparked by a re-analysis by Davey et al (2015) and Aiken et al (2015) of a pivotal study conducted by Miguel and Kremer in the 1990’s (published 2004). The reanalysis found little evidence for some of the indirect benefits of school deworming programmes, such as external benefits for non-treated schools and improved performance of children in school examinations.

The evidence behind the programmes is therefore highly contested. Just as there is evidence put forward that supports the approach, much of the evidence in fact contests, or at least does not support, many of the claims made. Anthropological and epidemiological evidence suggests that the public health programme of mass drug administration for intestinal worms does not work as those advocating for it suggest. Lock and Nguyen (2010) describe a similar situation in relation to HIV and anti-retroviral drug trials in Uganda. They argued that “Both the AZT and nevirapine trials show how framing a problem as a public health emergency can suspend some of the normal criteria by which biomedical efficacy is judged.” (p.194). In the case of neglected tropical diseases and in particular the diseases managed through mass drug administration, the “state of emergency”, was the extent of the suffering by people who are affected by these diseases through negative social, economic and political forces and through lack of safe water and sanitation. This justified the programmes irrespective of the limited or contested evidence (Molyneux et al 2012; Hotez, Mistry and Fenwick 2012³⁰).

²⁹http://www.theguardian.com/global-development-professionals-network/2015/aug/05/explainer-wormwars-deworming-science-kenya?CMP=new_1194&CMP

³⁰ Blog post: Deworming should remain an essential cornerstone for NTD control, posted 18th July 2012, <http://blogs.plos.org/speakingofmedicine/2012/07/18/should-deworming-policies-in-the-developing-world-be-reconsidered/>

Notably, these current debates are on evidence and data produced fifteen years previously. What can be said about the evidence from mass drug administration that has now been running for over ten years? There is little epidemiological data documenting infection rates over the period of mass drug administration (discussed in Parker and Allen 2014, Allen and Parker 2011), a situation which is discussed more in chapter five of this thesis. While there is some literature on the cost of implementing mass drug administration (Goldman et al 2007, Leslie et al 2011), the cost-effectiveness of the strategy will arguably differ depending on the baseline prevalence of infection in the population (Leslie et al 2011³¹). Published literature often illustrates the adverse social and economic effects of intestinal worms (e.g. Conteh et al 2010) providing justification for the strategy of mass drug administration (with assumptions on the programme working in practice, which has in itself been contested as discussed above in Allen and Parker's findings). However, it is difficult to find evidence *from* mass drug administration on its effect of improving social economic outcomes (Taylor-Robinson et al 2015). To do so, Conteh et al (2010) refer to a compelling economic analysis of the beneficial effects of hookworm eradication in the United States at the beginning of the twentieth century (Bleakley, 2007), the biosocial context of which is arguably very different to the settings where mass drug administration is rolled out currently. The other influential study is that of Miguel and Kremer (2004), the original study that has been re-analysed and contested, provoking the contemporary '#wormwars'. Despite so much focus on neglected tropical diseases and on the deworming programme in particular, there is little engagement with the realities of these diseases for the people affected by them or vulnerable to them (Parker et al, 2012).

³¹ Leslie et al showed that the cost effectiveness differed between school-based and adult treatments.

In these neglected tropical diseases programmes, the politics of poverty are never addressed, yet in the defining features, this is what perpetuates the inequitable distribution of these diseases among certain populations.

Farmer et al (2013) have argued that any disease is neglected in this context. Whether the disease is an acknowledged 'neglected tropical disease' or a disease disproportionately affecting neglected people, social determinants of health, as described by the WHO, underlie these health inequities:

“... the conditions in which people are born, grow, live, work and age, including the health system. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels, which are themselves influenced by policy choices. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries.”³²

These aspects are explored in this study. However, in this thesis I try to not delimit the social determinants from the biological determinants of disease as separate entities, rather (as argued in particular in chapter four) I look at where they interact. Despite the defining terms of neglected tropical diseases being embedded in these social, economic and political aspects of neglect and suffering, very little is written about the people who are vulnerable to these diseases. One such group of people are fisherfolk, a 'high risk' group targeted by mass drug administration. They are vulnerable to a number of the diseases due to the conditions in which they live and work, and they have been largely neglected by public health policy. Fishing livelihoods are often perceived as a different or particular way of life; a way of life

³² http://www.who.int/topics/social_determinants/en/

which shapes determinants of health inequity, and shapes their relationships with authorities and institutions, including public health.

FISHERFOLK AND HEALTH

Much of the literature on those involved in small-scale fisheries and health in sub-Saharan Africa comes from research along shores of large water bodies such as the Great Lakes in East Africa. This literature also tends to focus on HIV/AIDS. This partly reflects the findings that fisherfolk are at increased risk of HIV which is associated with particular aspects of their lifestyle and the nature of fishing livelihoods (Kissling et al, 2005). Additionally, structural factors exaggerate their lack of access to testing and treatment, and as a population they have been largely neglected by policy in the past (ibid.). For neglected tropical diseases, there has been research on schistosomiasis among those living and working along the shores of Lakes Victoria and Albert in Uganda in particular (discussed more in chapter four), but this largely focuses on the epidemiology, ecology, biology, disease and treatment³³. The context is different to where this study took place; however, there are illustrative points from this literature on fisherfolk and health elsewhere in Uganda and sub-Saharan Africa that relate more broadly to this thesis and to this discussion in the framing of global health problems.

³³ For example, a Scopus search of Lake Albert OR Lake Victoria, AND schistosom* returned 95 publications with only three relating directly to social aspects of disease and treatment in Uganda: Parker et al 2012 (based on long-term ethnographic research on the social responses to schistosomiasis and mass drug administration across three fishing areas on Lake Victoria, Lake Albert, and the Albert Nile) and Kabatereine et al 2014 (based on a cross-sectional, descriptive, questionnaire survey on perceptions, attitudes, practices and behaviours for schistosomiasis on the islands in Lake Victoria) and Muhumuza et al 2009 (a cross-sectional survey on socio-economic status and schistosomiasis). In addition, there were two publications from research in Kenya: Odhiambo et al 2014 (based on focus group discussions and interviews in an informal settlement in Kenya on attitudes and knowledge) and Omedo et al 2012 (on community health workers perceptions to mass drug administration based on unstructured open-ended interviews), and one in Tanzania: Mwanga et al 2004 (on perceptions, attitudes and practices assessed through in-depth interviews, focus groups, and a questionnaire).

The term fisherfolk is used to reflect the many people involved in varying capacities in the fish business and at fish landing sites. It is important to note however that they are not a homogenous or bounded population, far from it. The term is useful for denoting a concept of this heterogeneity of people involved directly and indirectly in the fish business. Some people move into fishing permanently, others temporarily, and many people are often termed 'fishing-farmers' (Geheb & Binns, 1997). In this thesis, I use the term interchangeably in describing people living and working along the River Nile in varying capacities. In this sense, it encompasses the term used in Moyo and Adjumani districts, '*meri ti ba*', or 'people of the river'; although with increasing fish markets many fishmongers also come from urban areas elsewhere to the landing sites.

From research along the lake shores, those involved in the fish business tend to be aged between 15 and 35 years (Seeley, Tumwekwase & Grosskirth, 2009). Many activities are carried out at fish landing sites by both men and women, with many fishers starting at a young age, learning from their peers. Fishing is usually carried out by men. Other related occupations such as fish processing (sun drying or smoking fish), fish trading and fishmongering are carried out by men or women. Other secondary activities often grow around the fish business at the landing sites, including market vending, and food and drink selling which tend to be by women. While along the shores of Lake Victoria there are larger landing sites, many fishers also operate from local village landing sites. In these circumstances fish may be prepared for home consumption or for smaller scale fishmongering.

On the larger lakes, such as Lake Victoria, commercial organisations pack and prepare the fish for sale further afield and for export internationally. Some of these landing sites have developed and are becoming increasingly 'urban', with an emerging leisure industry and urban culture as described by Beuving (2010). These

fish landing sites “can be vibrant centres of economic activity, attracting young people in search of independent lives and incomes for their families” (Westaway, Seeley & Allison, 2007 p.666). Despite this development, infrastructure at many landing sites is limited. This is often the case for water and sanitation, and therefore people are at increased risk of neglected tropical diseases including schistosomiasis and soil-transmitted helminths.

Fishing and the fish business is a livelihood strategy for many in poor, rural areas. In the face of extreme poverty some people are drawn into the fish business by a lack of alternative economic opportunities (Seeley et al 2009, Hüsken and Heck, 2012). Indeed, the lakes and rivers are a potential source of wealth, however this aspiration is not always realised. Compared to other economic alternatives often open to people in these settings, such as small-scale agriculture, most fishing-related activities provide daily cash income. Yet, while some fishers can become relatively successful, others continue to suffer adversity (Beuving 2010).

Many fisherfolk therefore engage in migration as a strategy for securing income and food. Yet this is also a source of risk and vulnerability in the fish business (Nunan 2010). With transient, temporary or informal lifestyles, people at fish landing sites are often seen to have poor social and political cohesions. Limited social capital and networks of trust have been associated with incidences of violence and abuse (Seeley et al 2009). Furthermore, Sunil (2007) describes how the relationship between fishers and formal institutions and state agencies are often fraught with conflict and lack of trust.

While fishing is a livelihood strategy for many, fish landing sites were also seen as ‘immoral places’ where people go as a ‘last resort’ (Pearson et al 2014). It is suggested that fishers have a relatively low status and lead a ‘marginal existence’

(Bene, 2009; Bene and Friend, 2011). Fishing camps and villages are often remote with poor immediate access to services including health centres in towns and trading centres (Hüsken and Heck, 2012). Additionally, Husken and Heck (2012) argued that fisherfolk have been excluded, by not being targeted through healthcare policies and programmes. Lungu and Husken (2010) argue that there has been a more broad institutional neglect whereby fisherfolk have limited access to other structures such as credit and loans. Therefore, it is not just physical attributes of marginality that impinge on how fisherfolk are perceived and their greater vulnerability to poor health outcomes, but structural marginality too.

Along the shores and out on the waters, fishers face other threats. Immediate dangers or threats to life include injury, drowning and attacks by hippos or crocodiles. Other risks or uncertainties are tied into the unreliable nature of the work (ibid; Bene 2003). These vulnerabilities include the unreliable weather and long-term climate change. Occupations at the landing sites are affected by changing fish stocks and the impact of extended or depleted rainy seasons and dry seasons. This increases the uncertainty of their livelihood and experience of adversity such as famine. Seeley et al (2009) argue that this high-risk environment is associated with low risk perceptions, seen through their perceptions of HIV risk.

In this context, landing sites are sometimes portrayed as places of risk-taking, alcohol use and casual sex, and therefore sexually-transmitted infections including HIV (Seeley et al 2009; Westaway, Seeley and Allison, 2007). Inherent in this risk are gender and power inequalities between those involved in the fish business (Williams, 2008; Luke & Kurz, 2002; Luke, 2003; Kwena et al, 2012). These inequalities have been described in fish transactions, including a much theorised 'fish-for-sex' phenomena at some fishing sites in sub-Saharan Africa (Bene and Merten, 2007). In the Kafue flats, Bene and Merten found that women who had

partners as fishers appeared to have better access to fish (Bene and Merten 2008). The authors described how if the fish catch is low, or competition is high with more people being drawn into fishing related activities, these transactions become more fraught, and people resort to transactional sexual relationships. At times this may be coercive, with fishers demanding sex before trading fish; 'so called fish-for-sex' (ibid. p.878). Within this relationship, Tindall and Holvoet (2008) argue that women are often in a weaker position, with limited bargaining power to resist the vulnerabilities they face.

However, others have pointed out that there are difficulties in delimiting transactional sex as many relationships in this context involve some sort of transfer of money or gifts (Kwena et al 2012; Harcourt & Donovan 2012; Luke & Kurz, 2002; Luke, 2003). Research on transactional sex outside fisheries has suggested that it is also a way for women to express agency and power (Wamoyi et al 2011). Furthermore, at the fish landing sites women are also seeking economic independence. There is opportunity and space for some women to be relatively successful, and at urbanising fish landing sites along Lake Victoria there are diverse ways of how women can earn a living (Pearson et al 2013).

There are therefore many reasons why fisherfolk are disproportionately more vulnerable to diseases like HIV, but also neglected tropical diseases, and many reasons why they face difficulties in accessing healthcare. The context is different in Moyo and Adjumani districts where the fieldwork for this thesis took place, compared to the sites described in the literature on fisheries along Lake Victoria. Rather than urbanising sites with limited social cohesion, they are rural fishing sites with many people best termed 'fishing-farmers'. There are many elements of neglect and marginalisation, and tensions with authorities as described in this

literature review. Yet there are also spaces for resistance, resilience, agency and power.

This thesis contributes to this literature by describing health and illness among riverine fisherfolk in the borderlands of northwestern Uganda. It goes beyond literature on HIV, focusing on other diseases that fisherfolk in this setting were disproportionately vulnerable to. For this study on neglected tropical diseases, I focussed on the livelihoods of those living and working along the River Nile, as it exemplifies many of the features of why some diseases are neglected. It provides a pertinent illustration of the need for taking a biosocial approach to understanding the complexities and realities of global health priorities, and an opportunity to subvert some of the assumptions held in these.

RESEARCHING HEALTH, ILLNESS AND HEALING AMONG RURAL FISHERFOLK

This study reflects on health, illness and healing among fisherfolk living and working along the River Nile in northwestern Uganda. This thesis describes the everyday reality of public health and neglected diseases in this context. It contributes to a growing interdisciplinary literature on global health and neglected tropical diseases.

Having demonstrated that there are discrepancies between the defining features of neglected tropical diseases and the interventions that are implemented – that is, the social, economic and political context of people who the diseases affect, managed by technical fixes delivering drugs as stand-alone programmes – in this thesis I explore the context and the reality of some of these diseases. In so doing, I demonstrate that the features that apply to neglected tropical diseases also apply to disease and healthcare more generally in this geographical context.

My research is an ethnographic-epidemiological study based in an area where a number of neglected tropical diseases are endemic and co-exist alongside each other and alongside other infections such as malaria, HIV and tuberculosis.

During ethnographic fieldwork in Moyo district in 2009 for an MSc in medical anthropology on the social responses to mass drug administration for schistosomiasis, with a District Vector Control Officer, we carried out a small parasitological survey on one fishing island. Surprisingly, we found a very low infection rate, which was in contrast to other fishing sites near Lake Albert in northwestern Uganda (Parker et al 2012)³⁴. The direction of this research emerged from this. Were there low infection rates along the River Nile as reflected in this earlier survey? If true, was this due to mass drug administration? It was clear that in order to answer these questions an epidemiological-ethnographic approach was needed. Epidemiology was needed to describe patterns of disease, but alone would not explain the reasons behind the results. Ethnography was needed to explore this, which alone would not ascertain the underlying presence or absence of disease. Therefore, how can we explain the parasitological results using an interdisciplinary, biosocial approach? From this I also developed an interest in exploring the disparity between global health rhetoric and local realities regarding neglected tropical diseases.

The research revolved around exploring social, cultural, political and economic conditions that place fisherfolk in positions of increased vulnerability to (or equally mitigated against) neglected tropical diseases. What is the reality of the global health concept of neglected tropical diseases for those vulnerable to them? The

³⁴ In Moyo, on one fishing island only one male fisher was found with schistosomiasis on stool microscopy out of 31 tested. This was compared to a market in Panyimur, where out of 120 traders tested, 90% were found with schistosomiasis (Parker et al 2012).

questions explored were guided by the research itself, in an iterative, inductive manner. What are the main health concerns among this population? How do neglected tropical diseases fit into this? What are people's understandings of health, illness and affliction and how have public health control programmes influenced changing attitudes towards biomedicine, changing attitudes towards and understandings of health and disease, and changing patterns of disease? What are people's attitudes and responses towards treatment options and providers? How is healthcare accessed and what treatment is sought when, where and why? Is engagement with fishing populations prioritised through global public health priorities, and what is the nature of the relation between fishing populations and public health or global health?

Ethnographic fieldwork was carried out and the research questions and research themes developed throughout the fieldwork process. It was guided by this inductive approach. However, the starting point for the study was through conducting an epidemiological parasitology survey on intestinal helminths among fisherfolk along the River Nile as there was limited epidemiological data on rates of disease. This addressed more specific questions: What are the key drivers of disease patterns among fisherfolk? What is the prevalence of *schistosoma mansoni* and other soil-transmitted helminths (*Necator americanus*, *Anclostoma duodenale*, *Ascaris lumbricoides* and *Trichuris trichiura*) among fisherfolk along the river? How can we explain the findings looking at the interaction between biological and social aspects?

While the research began by investigating schistosomiasis, from both the epidemiological survey and the ethnographic fieldwork, other diseases emerged as significant. A collection of diseases are described in this thesis: intestinal worms

(schistosomiasis), Buruli ulcer and hepatitis B. These diseases were concerns for people for different reasons. All three diseases in this geographical context affect rural people. Schistosomiasis and Buruli ulcer are more specific to the fishing population as their transmission occurs along the river. Hepatitis B is not specific for fisherfolk, although it does disproportionately affect rural areas in northwestern Uganda (Bwogi et al, 2009). The diseases vary not only in how they have been managed from a public health perspective, but also in how they are managed and perceived by the people who are vulnerable to them. The following provides a brief overview of the three diseases:

Schistosomiasis is a parasitic intestinal infection, and one of the neglected tropical diseases. It is transmitted along river banks in areas of slow moving water. It can have severe chronic complications affecting the liver. It is a well-known disease in Moyo and Adjumani with a long history, documented since at least mid-twentieth century (Nelson, 1958). Mass drug administration has been implemented to control the disease as a vertical intervention funded by international donors and pharmaceutical companies and delivered through the Ugandan Ministry of Health to primary schools and at risk communities in endemic areas.

Buruli ulcer is a bacterial skin infection, also a neglected tropical disease. Its transmission is associated with areas along river banks with slow moving or standing muddy water. It is also a long-standing condition in Moyo and Adjumani, with cases documented at least since the 1960's. From a global health perspective, it is managed through the Global Buruli Ulcer Initiative, although there is no specific control strategy in place in the districts, and it is largely managed by local herbalists.

Hepatitis B is a viral blood borne infection and it is not a neglected tropical disease. It is transmitted via blood and other body fluids. It can cause severe

chronic complications and death. Diagnostic testing was only introduced relatively recently to Moyo and Adjumani districts but the disease is likely to have been around for many decades. At the time of fieldwork, there was no specific control initiative introduced for adults (with vaccination only being provided through infant vaccination schedules since 2002), with limited services for diagnosis, investigations, vaccination and treatment through the Ministry of Health.

Comparing a long labelled neglected disease, with a so-called emerging neglected disease and a non-neglected disease, allows us to explore and analyse the global health concept, the realities of people exposed to and living with them, and to compare and contrast the global with the local perspective.

THESIS OUTLINE

This introductory chapter has summarised the key features of global health and the neglected tropical diseases paradigm that have shaped how particular health concerns are viewed and the solutions that have been implemented. It has outlined some of the key contemporary debates on one of these strategies, mass drug administration to control intestinal helminths; debates that are situated within disciplinary boundaries. Beyond this, it has discussed the literature on health and fisherfolk, a group vulnerable to many of the neglected tropical diseases and a population that exemplifies the features of why some people are affected by these diseases. However, there remains a paucity of research on riverine, small-scale fisherfolk and neglected tropical diseases, and a paucity of interdisciplinary research into this global health concept, which this thesis begins to address.

Chapter two, "*Researching public health: methods, ethics and interdisciplinary working*", outlines the interdisciplinary approach and methods used in this research. In doing so, it analyses methodological and ethical issues that arose

during the fieldwork process. It relates this to biomedical and epidemiological norms that predominantly guide research on health, and the reality of how these are formed and shaped in practice. It argues that while an interdisciplinary approach is fruitful for exploring global health concerns, this is not without difficulties. However, the areas of tension that arose between ethnography and epidemiology provided insight into the practice of researching global public health that informed the research more broadly.

Chapter three, “*Meri ti ba’: making a living along the river*” begins by describing the social, economic, political and historical context of Moyo and Adjumani districts. It describes fishing livelihoods, and how people along the river (*meri ti ba* in Madi language) relate to each other and to authority. It demonstrates how within this context of neglect and marginalisation, there are sites of everyday resistance and agency. Furthermore, in this context health and healthcare are largely seen as a right.

Chapters’ four, five and six analyse empirical findings on the three diseases, each illustrating different aspects of global health concerns. Trust, knowledge and power feature in much of the discussions and analyses in the chapters. For an interdisciplinary approach, the methods chapter demonstrates tensions in carrying out interdisciplinary work. However, the empirical chapters demonstrate the additional fruitfulness of this approach. It benefits our understanding of what has enabled success of a control program (schistosomiasis), why people make certain healthcare decisions (Buruli ulcer), and what is actually concerning the population and how they make sense of their concerns (Hepatitis B). These chapters are each describing very different diseases and through this description they tell the story of these diseases as they are controlled or emerge, understood and managed. They therefore present a collection of problems (Farmer et al 2013). I have not written a

separate chapter on witchcraft and local healing practices as separate entities, but I discuss these within the chapters where relevant, alongside other forms of illness, healthcare and healing in the everyday.

Chapter four, "*Mass drug administration: is it successfully controlling intestinal schistosomiasis?*", focuses on schistosomiasis and mass drug administration, following on from the discussion in this introduction on how global health structures and priorities have shaped the response to controlling this disease. In this area, contrary to what one might expect, there appears to have been success in controlling schistosomiasis. Explanations are given for this situation, which situate the success of mass drug administration within the social context of biomedical healthcare use, migration and movement patterns, the local economy of the fish business, and water, sanitation and hygiene practices. Schistosomiasis is therefore a neglected tropical disease that is arguably not so neglected anymore.

Chapter five, "*Buruli ulcer: an emerging public health concern?*", focuses on another neglected tropical disease, Buruli ulcer. The chapter argues that far from being a traditional health belief, the use of local herbalist treatment for Buruli ulcer is in fact in large part a rational choice given experience passed on through the generations, and lack of trust or confidence in the biomedical public health system alone. It is an 'emerging public health concern' in global health and a neglected tropical disease for the district health staff. However, for those living and working along the Nile, it is neither emerging nor perceived as neglected.

Chapter six, "*Hepatitis B: a 'silent epidemic'*", focuses on Hepatitis B which is not a neglected tropical disease, but has been arguably neglected. It illustrates the parallels with the emergence of HIV/AIDS as a public health concern and documents how this previous experience has shaped current understandings and responses to

Hepatitis B. It critiques the misleading term ‘neglected tropical disease’, in line with Paul Farmer’s critique, that diseases that afflict the poor, are by definition neglected. However, it goes further by exploring what has led to a situation where other diseases, such as hepatitis B, can become ‘neglected’ and emerge as new phenomena. While hepatitis B has been described as a ‘silent epidemic’ due to a biological silence (WHO 2013) and a social silence (Muraskin, 1988), I suggest there has also been a structural silence. Hepatitis B is not a neglected tropical disease, but arguably fits the concept.

Chapter seven, “*The neglected tropical diseases paradigm*”, concludes by critically reflecting on this. In this chapter, I summarise the themes that emerged from the research including the role of evidence in global health. This is seen through both the evidence that informs global health strategies, and also the evidence that informs local responses to health concerns and how people make sense of their interaction with development and global health. Disparities appear between the global health arena and the local context.

The overall argument of this thesis relates to the framing of neglected tropical disease. Grouping together the diseases has had dramatic effects in raising the profile of the diseases, and has paved the way for global attention, pharmaceutical and donor action, and increased research. These arguments are based within frameworks of social justice, of equity and fairness in health. Yet the underlying conditions that lead to inequities in health are not addressed. While one disease is controlled, another emerges. What is neglected from a global health point of view is not necessarily what is neglected from the population’s point of view. And in the middle, district and clinical staff are patching up the wounds as they present to them. While there is a role for vertical health programmes in some situations, there is a need to address the underlying structural conditions that constrain

improvements in health and equity. In implementing vertical health programmes, there must also be a serious engagement in horizontal healthcare.

This thesis contributes methodologically to interdisciplinary research in global health. It contributes empirically to biosocial research on neglected tropical diseases. Theoretically, it critiques the restrictive gaze in framing global health problems.

2. RESEARCHING PUBLIC HEALTH: METHODS, ETHICS AND INTERDISCIPLINARY WORKING

“It is difficult to make these fishers wait; you must take them when you can. This random sampling is what they say there in Kampala, but in the community it is not like that” [Vector Control Officer]

While conducting ethnographic-epidemiological research, I found myself grappling with methodological and ethical situations that made me reflect on divergences between biomedical norms in research and the realities of these in practice. These encounters, such as implementing random sampling and informed consent in this setting, highlighted the complexities of applying epidemiological ideals. I also encountered tensions in my own positioning as a biomedical and ethnographic researcher.

This chapter critically reflects on the methods, ethics and the process of conducting interdisciplinary research, analysing some of the tensions that occurred at the interface of this (Inhorn & Wentzell, 2012). I use the term interdisciplinary as opposed to multidisciplinary. Rather than employing different disciplinary methods as separate components of the research, the disciplinary methods of ethnography and epidemiology were intrinsically linked throughout conceptualising, conducting and analysing the research. It is also interdisciplinary research because as a researcher I have a background in both medicine and medical anthropology.

Regarding interdisciplinarity, Paul Farmer (1999, p.5) says:

It “is not meant to free the author from the responsibilities of discipline. Rather, it is clear to me that the disparities of risk and outcome described here are embedded in complex *biosocial* realities. To understand these realities, nothing less than a biosocial analysis will do - an analysis that draws freely on clinical medicine and on social theory, linking molecular epidemiology to history, ethnography, and political economy. Of course, such a synthesis is easy to demand but harder to produce; Fineberg and Wilson have termed it the “Holy Grail” of epidemiology.”

With this framework and caution, I reflect here on the process of producing interdisciplinary research. The starting point for this research was in investigating schistosomiasis and its control which required an epidemiological study to assess levels of infection among fisherfolk. By providing in-depth local knowledge and critical analysis on public health institutions, ethnography was used for understanding why public health programmes work in some settings but not others, and to explore the local meanings of global health priorities.

However, interdisciplinary working, while rich and productive (as demonstrated in this thesis) is not without difficulties. Many of these difficulties are framed within the fundamentally different approaches of biomedical and anthropological inquiries (Inhorn, 1995). Firstly, epidemiology studies disease whereas anthropology studies illness. However Kleinman, although putting forward these concepts, cautions against using them as a dichotomy (2013). Rather they are meant to facilitate richer understandings of experiences. Secondly, epidemiology takes a reductionist and positivist approach, whereas anthropology takes a holistic and humanistic one. Thirdly, the methods employed differ and risk is conceptualised and instrumentalised in differing (individual and structural) ways (outlined in Inhorn 1995). However, Inhorn (1995) argues that these often cited divergences between

epidemiology and anthropology can in fact be viewed as areas of convergence. Both fields study populations rather than individuals, and both investigate the broader determinants of health. Furthermore, medical anthropology and public health (which epidemiology often works within) are inherently interdisciplinary disciplines. Embracing these “productive tensions” leads to more avenues of inquiry (Inhorn and Wentzell, 2012).

Farmer (2013) argues that the framing of global health as a ‘collection of *biosocial* problems’ (adapted from p.xiv) provides opportunity to forward an interdisciplinary approach. Interdisciplinary, biosocial approaches have been advocated for in global health generally and neglected tropical diseases in particular (ibid.; Allen and Parker, 2011; Reidpath, Allotey & Pokhrel, 2011). On the other hand, global health is influenced by biomedical frameworks, having developed over time from colonial medicine, tropical medicine and international health (Greene et al, 2013).

Developing from these roots, many research priorities in global health, like health research more generally, are based on biomedical norms (Lock and Nguyen, 2010). There are therefore a number of areas for critical reflections.

There are a number of consequences of a biomedically driven evidence-based medicine model in global health. The rise of evidence-based medicine in global public health has led to the hierarchical placement of different types of evidence and the priorities of reliability, validity and generalizability. In this regard, Lock and Nguyen (2010) have cautioned on the market-based proliferation of clinical trials in developing countries: “Global health inequities in access to biomedical care are therefore a powerful driving force behind the globalisation of clinical trials” (p.190). One consequence is that biomedical and statistical norms influence the way that health research is conducted. A further consequence is the way in which healthcare is conceptualised and provided. Adams (2013) argues that this has led

to an “experimental metric as a means of providing health care” and “a shift in the priorities of caregiving practices in public health such that “people [no longer] come first”” (p.54-55).

Further to this, bioethical norms are also central to global public health research. In so being, Farmer and Campos (2006) have argued, bioethical debates have centred largely on concerns of the few in rich, industrialised nations, with neglect of the rights of the many poor and marginalized people in developing countries who by and large suffer from the greatest proportion of ill health, disease and poor health outcomes. While biomedical care and experimental medicine have developed along with bioethical frameworks, both research and ethics have been problematic considering global health inequities. In response to inequities in bioethical debates, Farmer and Campos argue that the challenge is to “*resocialize the way we see ethical dilemmas in medicine*” (p.262, italics in original). Thus re-situating the local relevance of the rules and practices of ethical codes, protocols, and information and consent procedures and how these unfold in practice (Ulrich, 2011; Harper 2007).

A further point of critical reflection therefore arises from within this debate of evidence-based medicine, bioethics and global health. Scholars have framed the processes of conducting research and implementing bioethics as exemplifying the imbalance of power. This is particularly the case in transnational research, where research from industrialised countries is implemented through and in developing countries (White, 2011).

The analyses also raise important issues on what makes up the evidence behind global health interventions which speaks to contemporary debates in global health on neglected tropical diseases. Is this another form of one-size-fits-all that does not

represent local context? In pursuing robustness, reliability and generalisability, are studies so removed from real-life that they no longer represent reality? What are the driving forces behind the norms of evidence-based policy and evidence-based public health? How are these norms played out in practice by those participating in the research (by researchers and those being researched)? Many of these became pertinent questions during fieldwork, while analysing and writing this thesis. This chapter does not address them all, but these questions influenced my decision to turn the social analysis on to the methodology and processes of data collection.

This chapter is largely a confessional tale (Van Maanen, 1988), describing some of the methods, ethics and processes of carrying out interdisciplinary research. I first outline the fieldsites and methods used in the study. I then discuss some of the practical difficulties of health research in this rural setting that require a rethinking of some standard research practices. Methodological and ethical practices are addressed. The focus is on specific encounters from one component of the fieldwork: an epidemiological survey for schistosomiasis and other soil-transmitted helminths among rural fisherfolk. Reflecting on the research processes and methodologies, and drawing on anthropological work on medical research in Africa (Geissler and Molyneux, 2011), it explores the divergences between expectations from public health research priorities and the realities of conducting such research. The purpose is to engage in a critical analysis on the process of information gathering that ultimately informs public health policies.

I then critically reflect on my own experiences of being an interdisciplinary field researcher. Being trained both in medicine and anthropology, I found myself grappling with internal conflicts while situating myself in the field. While I went in with a clear idea that I was a researcher with a medical background, I found particularly in the first few months that I continually had to re-stake this position.

This led to both personal and professional dilemmas which bear relevance to debates on medical and anthropological research in areas of abject poverty in the context of which many people suffer from neglected diseases. My interdisciplinary background also influenced my approach to writing up and presenting the data. I therefore examine some of the struggles in writing, in particular between stances of objectivity and subjectivity, of different ways of knowing in biomedicine and anthropology.

I conclude with a discussion on the relevance for researching neglected diseases. I demonstrate that while global health problems are framed within a biosocial analysis which requires an interdisciplinary approach (Farmer et al, 2013; Parker and Allen 2012), this is not without challenges. However, these challenges in themselves provide further emphasis for the need to employ such an approach, the basis of the findings presented in this thesis.

FIELDSITES AND METHODS³⁵

The fieldsites are discussed in more detail in the following chapter, but I provide an overview here in order to illustrate the context in which ethnographic-epidemiological fieldwork took place. Ethnographic research was undertaken in 2013 to 2014 in Moyo and Adjumani Districts in northwestern Uganda which border South Sudan. A preliminary report from the most recent census in 2014 estimated the population of Adjumani to be 232,813 (UBOS 2014 p.20) and Moyo to be 137,489 (UBOS 2014 p.21). Adjumani has ten sub-counties and Moyo has nine. In each District, five sub-counties border the River Nile. In Moyo District, Obongi County comprises three sub-counties all of which are situated along the river. In

³⁵ Part of this sub-section was written for a paper titled, "Low prevalence of intestinal schistosomiasis among fisherfolk living along the River Nile in northwestern Uganda: a biosocial investigation" (forthcoming).

the other sub-counties in Moyo District and those in Adjumani, the people are predominantly from Madi clans. In contrast, in Obongi people are from many ethnic groups from West Nile and South Sudan aside from Madi, identifying as Aliba, Aringa, Gimara and Reli. In these sub-counties people spoke many languages in addition to Madi. In all the sub-counties some people also spoke English and Ki-Swahili.

The region has a long history of social upheaval (Allen 1996; pp 220-261) and marginalisation economically and politically (Allen 1991; Woodward 1991). During conflict in the 1980's, the majority of the population in both districts fled into southern Sudan (now South Sudan) or Zaire (now Democratic Republic of Congo). Throughout this period, a few remained or returned before mass repatriation in 1986. In the 1990's and 2000's, a large number of refugees from southern Sudan settled in both districts, but have since repatriated. However, the situation changed again in December 2013 when tens of thousands of refugees from South Sudan fled into Adjumani District.

The majority of people are living by subsistence farming of crops such as cassava, sweet potato, maize, groundnuts, sesame and various green-leafed vegetables. Their staple diet also includes beans. Fish is relatively expensive in the town, but part of the daily diet along the river. Rice, pumpkins and tomatoes are grown in swamp areas along the river bank. Near the river, cattle graze freely or are herded by young men (often from Western Uganda, or male family members). People are drawn to livelihoods along the river, with its fertile lands, food sources and opportunities to make a living.

The two districts are separated by the River Nile, which lies at less than 3000 feet (around 900 metres) above sea level (Hall and Langlands 1975). There are two main crossing points for vehicles: Laropi and Sinyanya, both of which are served by

a Uganda National Roads Authority ferry. At many other sites, people plus their luggage, livestock, bicycles and motorbikes cross, either by motorboat or rowed canoe. Motorboats also cross from both districts to Nimule, a busy border market town in South Sudan. This is a popular trading route, and during fieldwork an increasing number of motorboats served these crossings.

Geographically the districts differ. Moyo is a mountainous region with a lowland area along the river, whereas Adjumani is predominantly savannah grassland. The southerly part of Adjumani District is Zoka Forest, an uninhabited area that had previously been an area where sleeping sickness was prevalent. Sleeping sickness campaigns were carried out in the early twentieth century. During fieldwork, an elder reported that at the turn of the 19th and 20th century, due to the abundance of tsetse flies and the transmission of sleeping sickness (Human African trypanosomiasis, HAT), the British administration moved people previously settled there.

In fact, the districts are endemic for many neglected tropical diseases, including *S. mansoni*, soil-transmitted helminths, lymphatic filariasis, onchocerciasis and human African trypanosomiasis. Mass drug administration occurs for the first four. District Vector Control Officers oversee the mass drug administration, as well as vector surveillance activities for onchocerciasis and human African trypanosomiasis in particular.

During fieldwork, six fish landing sites (*oti*) were followed up in each district. The sites varied in nature. The majority were associated with a village. Two were a number of kilometres away from the nearest village and people had put up temporary houses at the sites. One was an island throughout much of the year, only passable by land in the dry months (January to March). Fishermen and female fishmongers stayed at the landing sites for days, weeks, or months at a time, in

small grass-thatched houses (*tukuls*), under shelters or out in the open. From some sites, islands and reed banks were reached where fishermen stayed overnight or weeks at a time before returning to the mainland.

The fish landing sites were also used for many domestic purposes such as collecting domestic water and washing clothes. In addition, people operated small businesses, selling cooked food, tea, soda, sachets of alcohol, soap and cigarettes. At some sites, women sold locally brewed alcohol: local gin from cassava (*waragi*) or local wine from passion fruit.

ETHNOGRAPHIC-EPIDEMIOLOGICAL FIELDWORK

Building on three months of previous fieldwork in Moyo District in 2009³⁶, I returned to carry out a further sixteen months of ethnographic-epidemiological fieldwork in 2013 to 2014 this time in both Adjumani and Moyo Districts. Four of these months were spent in and around Kampala and Entebbe organising the research. During this time, I established links and liaised with relevant Ministries (Vector Control Division, Ministry of Health) and research groups (Social Science Programme MRC/UVRI). I submitted my proposal to an Institutional Review Board to obtain the necessary ethical clearance, and once that was obtained I applied for research clearance.

The process of obtaining ethical and research clearance in itself shaped the research proposal. The research was originally conceptualised as an ethnographic study. As there was limited data on schistosomiasis infection rates among adults in the region, in order to ascertain background data on the prevalence I included an epidemiological survey to be conducted through District Vector Control as part of the methods. As the research contained this epidemiological component medical

³⁶ MSc dissertation, Pearson, 2009.

ethical clearance was required. During this process the proposal was rewritten and effectively turned on its head. The focus of the proposal became the epidemiological component of the research with the ethnography becoming a part of the methods, but not the essence. This shaped the fieldwork. The survey was organisationally a large part of the research, and ethnographically a part of the analysis in itself. In this respect, the ethnography is not just a study of health, disease and illness among fisherfolk in the districts, but an ethnography of the interface between fisherfolk and public health as it is practiced through forms of healthcare and research.

I moved to Adjumani District in July 2013 having reconnected with a researcher I had met and worked with in 2009. I rented a house from a family who lived in a village just outside the main town. This is where I lived for the following twelve months. While I was often away at the fishing sites or staying in Moyo district, the family welcomed me into their home. When I had time off, I often sat with the elder grandmother. She did not speak English and helped me to learn some of the Madi language. In the final few months of my stay there, the family also rented out one their houses to Ugandan medical humanitarian workers who had come to provide medical assistance for South Sudanese refugees. Just by the home was a relatively busy daily market and when I was in Adjumani I visited here nearly every day.

In Adjumani and Moyo Towns I spent time with the district staff, in particular the District Vector Control Officers. In the first few months, when in Adjumani town I spent one day a week at the district hospital visiting the medical ward or outpatient clinic. The research predominantly involved visiting twelve sites along the River Nile in both Adjumani and Moyo Districts, and so our time was split between the fishing sites, and the towns of Adjumani, Moyo and Obongi. I sometimes stayed in Moyo

Town, Laropi trading centre or Obongi Town, the latter two being situated along the river with many nearby fish landing sites. When researching in Obongi or Laropi we often stayed for a week or two, spending time in the trading centres, at the ferry landing sites and other nearby fish landing sites.

In devising the research protocol, I thought about focussing on one fishing site, living and conducting an in-depth ethnography at one site. However, following the survey, the ethnography developed from many perspectives. Therefore, I continued with a multi-sited ethnography, gaining insight into life along the river, the local fish business, health and healthcare along the river, as well as at the district level. This did involve moving around between different sites, but in the context of the local fish business this is not an unusual occurrence. Sometimes I met fishmongers I knew from the fishing sites selling dried fish at the daily market by my house in Adjumani. These meetings away from the landing sites helped consolidate relationships I was building through the fieldwork. Not only this, I met fishermen from one landing site at others. I also met fishermen and fishmongers who I had known in 2009. All in all, while being a multi-sited, multi-level ethnography, these connections and re-connections helped in developing relationships with the fishermen, fishmongers, district staff and health staff. All of this added to the ethnographic understandings of life along the River Nile that are an integral part to this thesis.

Throughout this time, I worked closely with two local researchers. One was an elder who had extensive knowledge of the Madi people and the two districts. The other had a good understanding of my research, having worked together during fieldwork in 2009. They were both male. Men and women were happy to discuss openly with us, especially as we all spent repeated and prolonged time at the landing sites both formally in conducting the survey, and informally. Both

researchers were great conversationalists, and we spent days at the landing sites, chatting and conducting interviews.

I learnt some of the Madi language³⁷, but it was not enough to conduct in-depth interviews. By the second half of my stay, during days spent observing water contact at the Madi landing sites I could follow most conversations and bargains for fish, but as soon as we moved on to the four sites in Obongi County where people conversed in other languages, my language skills were too limited. Yet, particularly in Obongi, there were a number of people who spoke good English and so some conversations and interviews were held in English, particularly with local leaders and people from older generations. However, the majority of interviews at the landing sites were translated through one of the local researchers. The researchers also conducted interviews alone. Conversations and interviews with district and health staff were in English.

The ethnographic fieldwork included participant-observation, group discussions, open-ended unstructured and semi-structured interviews with key informants at the landing sites (fishermen, fish-processors, fishmongers, local council members, Beach Management Unit members and elders) and district authorities (in Health and Fisheries), health workers and local healers. Interviews were not recorded in order not to disrupt the flow of natural conversations. When appropriate, notes or jottings were taken at the time and written up in full afterwards. Fieldnotes were written at the end of each day.

Many of the discussions and informal conversations at the landing sites occurred publicly, often with us joining in with conversations while waiting for the fishermen to arrive, or while the fishermen were 'taking tea' having returned from the river.

³⁷ Of the Madi language, I learnt greetings, common questions and answers, how to get by at the markets, and words and phrases related to fishing and health.

The landing sites were often busy, with people coming and going, and so the conversations were often informal. They frequently ended up being discussions with groups of people. At times this was two to three people, at other times twenty. We would let the conversations be guided by what people were willing and at ease to discuss. To maintain confidentiality, we held some conversations and interviews with individuals in private settings. At the fishing sites, having private conversations was sometimes difficult, and so if needed we would arrange to follow-up with people at another time and place. One time, this was on the veranda outside my house by the local market where one woman had come to sell her fish, but more often than not we found a quiet corner at the landing site or went to people's homes.

In one instance, the quest for privacy and confidentiality raised suspicions. This is discussed in more detail in chapter six. Having been given directions to the home of a woman and her husband who we had arranged to follow up in private, we found that both were not around. We did not inform those around of the particulars of our visit, but it did not go unnoticed. When we returned at a later date, we discovered that our previous visit had had unintended consequences. At a neighbouring home where we stopped to greet as we passed, as was often the case people asked who I was and what I was doing. We explained that we were doing research at the fish landing sites. Even though I was not there as a clinician, I was often introduced as *daktari*, a doctor, as this was my primary qualification. People started putting pieces together. Why was a European doctor coming to see this woman? It must be something serious, like hepatitis B. Rumours began to spread, which we only realised when we returned the following week.

Not only did this illustrate the potential for unintended consequences of pursuing research in a particular way, but it brought out people's immediate concerns. Fear

of 'this new deadly disease, hepatitis' was widespread in the areas where we worked, and became a theme we followed up on during the course of fieldwork. The episode also highlighted people's perceptions and expectations of researchers, in particular foreign researchers. For those not directly involved in our research at the landing sites, and therefore not fully aware of the research focus, there was an expectation that I must be working on 'serious' diseases like HIV or Hepatitis. Why would a white researcher be coming to the home for anything less serious, for worms? At one time, bilharzia had been thought of as a deadly disease affecting people in this area, now the concern had shifted elsewhere.

CROSS-SECTIONAL SURVEY

From October to December 2013, with the two researchers and a team of laboratory technicians (three in Moyo and four in Adjumani) including the Vector Control Officers, we conducted a cross-sectional survey at the twelve fish landing sites. With limited baseline data on local disease rates especially at fishing sites, a broad geographical area was surveyed. The sites were purposefully chosen to represent each sub-county along the River Nile plus initially two islands. A few weeks before the survey, one island flooded and everyone dispersed. Therefore, we chose another fishing site. 383 adults participated (203 males and 180 females), aged 18 to 75 years with an average age of 36 years. Around 30-50 adults participated from each site with, where possible, equal numbers of men and women.

It was difficult to collect baseline population data for the landing sites as the population was constantly changing. Random sampling was attempted at some sites, but this was not always possible therefore convenience sampling was adopted. The objectives were to reduce bias towards stable populations, and to

enable adults to participate who would ordinarily miss such programmes in a village because of their involvement in the fish business at the landing sites.

The researchers interviewed participants in their local language using a structured questionnaire (appendix 1). This documented demographic details including age, sex, education, ethnic group, occupation and number of children. In addition, details were obtained on medication use (praziquantel for schistosomiasis and Coartem³⁸ for malaria), use of local herbs, health status, water and latrine use, and factors relating to the fish business (landing sites used, time of day at landing sites, fishing methods used, frequency of using the landing sites, and number of years fishing or in related occupations).

The parasitological survey was carried out in collaboration with District Vector Control, with district health staff and laboratory technicians, and with technical assistance from Vector Control Division, Ugandan Ministry of Health. Each participant gave informed consent. An information sheet on the study (appendix 2) was explained to each participant in their language. Either a signature, or for those who could not read or write, a thumbprint was taken to confirm consent. Each participant provided a stool sample. Two Kato-Katz slides (with malachite green) per sample were examined. All slides were examined in the field for hookworm and reviewed the following week in the hospital laboratory for *S. mansoni*. Ten percent of the slides were cross checked at Vector Control Division in Kampala for quality control. Individuals diagnosed with intestinal helminths were followed up and offered treatment as per current guidelines (WHO, 2006).

In addition, water contact observations were carried out from approximately 6am to 6pm on two consecutive days at ten of the fish landing sites. These observations documented the time of day of contact with river water, the body part immersed,

³⁸ Artemether-lumefantrine

length of immersion time and the activity being carried out. General observations were also made on each visit to the sites. Detailed water contact observations were not carried out at two of the landing sites, as during this period of fieldwork the majority of landing site users had moved to other sites or to cultivate in their fields.

I carried out the observations on most occasions. I sat in view of the landing site, with the fishmongers and other women around. One of the researchers chatted informally, conducted semi-structured interviews or gathered other information. At some fishing sites, two landing sites were used and so we both carried out the observations. We carried out the detailed observations towards the end of the fieldwork period having already spent nine months visiting the landing sites. It was a formal exercise, as we sat with a pen and notebook, but by this point in the fieldwork this was not seen as unusual for us. By this time, people knew us and they knew our work on bilharzia and health. We carried it out as informally as possible, using it as a way to spend time at the landing sites with people there, chatting, taking tea, eating lunch and drinking soda. At most sites people carried on as they had on other visits, busy with fishing, washing clothes and cleaning fish. At one site, on the first day some did question the purpose of our activities but their suspicions soon faded on the following day as will be discussed in chapter three.

Throughout fieldwork, data was triangulated using multiple sources. These included available laboratory records from local health centres, semi-structured interviews with key informants at the landing sites, interviews with district and health staff, and ethnographic fieldnotes of informal discussions and observations.

Data collection and analysis was an iterative process. The survey questions were in part informed by previous ethnographic fieldwork in 2009 and certain aspects of

the Demographic Health Survey³⁹. The survey findings were explored through further ethnographic fieldwork. A descriptive analysis⁴⁰ was carried out on the cross-sectional survey data. An inductive thematic analysis of the fieldnotes and interview transcripts was carried out manually. Additionally, the epidemiological survey was also a site for ethnographic reflection and analysis.

DOING EPIDEMIOLOGY

In this section, I reflect on the epidemiological component of the research as a site where ethnography and epidemiology intersected. I examine how the theoretical epidemiological concept of random sampling and the bioethical concept of informed consent were practiced, how people responded to them and what shaped these responses. My aim is not to provide solutions to problems, but to describe the situation and reflect on what this means for research and ethical procedures. I also relate this to reflections on healthcare more broadly.

Working with a local team of researchers was enlightening for this understanding. Travelling to and from the landing sites each day we had many conversations, related to the research or other matters more generally. The district staff implemented the health programmes such as mass drug administration, and conducted research such as the parasitological testing. They were in a crucial position applying theory into practice. The majority of the district and health staff were people from within the district. Those who made up the survey team grew up and lived in the districts and they have relations in many villages. At the landing sites, they often made connections with people through the marriages of relatives. One researcher had worked with non-governmental organisations during exile in

³⁹ Model questions available at <http://dhsprogram.com/publications/publication-dhsq7-dhs-questionnaires-and-manuals.cfm> [last accessed, 29.09.2015]

⁴⁰ Using Microsoft Excel

southern Sudan in the 1980's and afterwards across both Adjumani and Moyo districts and knew the area particularly well.

Likewise, the laboratory technicians worked in laboratories and health centres across the districts. Some had been involved in re-establishing health services in the 1990's and early 2000's in the area following repatriation from southern Sudan. The laboratory technicians were also trained in biomedicine and some were undertaking further studies in public health and epidemiology. Additionally, they conducted other medical research especially for neglected tropical diseases (river blindness and sleeping sickness in particular). For the Vector Control Officers in particular, their day to day job involved understanding the theory and practicalities of implementing health programmes and conducting research in this setting. It was therefore an invaluable experience working alongside them during the research.

METHODS

For the epidemiological survey, the need to collect robust epidemiological data and the need for a more reflexive, flexible approach to collecting data given the dynamics of the local fish business, seemed to be in opposition to each other. We experienced methodological challenges around the sampling framework, the sample size and random sampling techniques. During fieldwork it became evident that these public health priorities had a different relevance for biomedical reasoning (seen through the ethical committee), compared to the practicalities of conducting research (seen through the district and health staff) and people's responses to the research (seen through the fisherfolk). The research experiences presented here suggest that engaging in an interdisciplinary, biosocial approach to global health and neglected diseases would require greater flexibility than some public health research priorities allow. Despite the objective biomedical frameworks, conducting epidemiological research was a social process.

One of the challenges in the epidemiological approach was the notion of generalisability. Lock and Nguyen (2010) discuss this in detail. While much of their discussion is on the rise of evidence-based medicine (EBM) and clinical trials, the principles of EBM are applied to other forms of research, such as our epidemiological survey. Countering the prominent aspects of EBM, including objectivity, randomisation and generalisability, Lock and Nguyen argue that the pursuit of these ideals in scientific evidence-making, 'biosocial differentiation' is "automatically ruled out as valid evidence" (p.188).

Our struggle with rolling out the cross-sectional parasitological survey across all sites was in situating the study within the social context. While using a particular sampling approach (i.e. not random sampling) rendered the results not generalizable to the wider population, I would suggest that in being sensitive to the situation it makes the results more inclusive and representative of those at the fishing sites who we were asking to participate in testing. It was therefore appropriate for the purposes of this study.

The fishing sites had many common attributes, but were also vastly different in many ways. It is this complexity, or heterogeneity, which was explored through ethnographic research at the sites, and is discussed in more detail in the following chapter. Some aspects that affected the epidemiological method included whether people stayed at the sites or not, how busy the fish business was, and who was involved in the fish business and how. Because of these differences, it was impossible to adopt one technique of random sampling and apply it to all fishing sites unaltered. Conversely, to choose sites based on similarities that would make it possible to deploy random sampling effectively would have excluded a large number of people from the survey - arguably the people most vulnerable to neglected diseases.

Flexibility and responsiveness to the local context was therefore needed, attributes that are inherent in an inductive ethnographic approach. The survey results are the best available data on contemporary levels of infection among adults along the River Nile in this region. This is used to determine the level of infection among fisherfolk across these sites, however generalising beyond this, not just for methodological reasons but also because of the variable nature of disease patterns, was not the end in itself.

From an epidemiological view, conducting the research required a re-socializing of the principles behind sampling. The other side to this was that participation in research was also a social process. Within global health research Lock and Nguyen argue that “biomedical knowledge-making is increasingly dependent on social processes that inadvertently make populations available for observation and experimentation” (p.188). Thus, I want to reflect on the survey in light of what it meant for those participating in it. Reflecting on positions of power, understanding the survey from the point of view of those being asked to participate in the research, sheds light on important aspects of how and why people respond to research programmes in particular ways.

For schistosomiasis in particular, people had limited access to stool testing ordinarily. Therefore, people responded positively to the survey at the landing sites. As one female fishmonger said: *“If you tell us the date we will be here, only not if there is a funeral, but otherwise we will come”*. Despite this eagerness for knowledge on disease status, people are trying to eke out a living from the river and as the opening quote suggests, interrupting that was not a practical assumption, despite the programme being in demand. It was not feasible to ask fishermen to wait before going out to the river, or request fishmongers to wait before heading to buy fish or take it to market. If people were unable to attend the survey

themselves or hadn't been able to provide a stool sample, they gave their sample pot to another person⁴¹. It was difficult to turn people away who wanted to be tested, especially as these opportunities rarely come along. The survey teams were eager to enable as many people as possible to be tested, within practical limits.

For epidemiological purposes, a large enough sample size was needed for robustness and significance. For district researchers there was additional importance. As in other studies, the research programme merged into a form of healthcare (Leach & Fairhead, 2013)⁴². Not only do research programmes provide healthcare, both research and healthcare have an experimental element (Adams, 2013). The clear distinctions made and explicitly written into the informed consent document for the research protocol did not translate into the realities of what a research programme like this offered to people: the chance to test.

Even taking the flexible approach of convenience sampling, it was not feasible to test everybody at each landing sites. Limits on finances, time and personnel meant survey participation had to be rationed. It was often explained to people therefore, that those who were tested 'represented the community'. While this made sense from a research perspective, it left some people feeling that they had missed out. Some people accepted the explanation, but others were understandably dissatisfied. People often reported shortages of medicines and diagnostic tests at the health centres. Being turned away from the survey was another example of the limited resources in biomedical healthcare. It therefore raised the question as to how the research programme influenced people's trust in, and perceptions of,

⁴¹ Often people gave the name of the original person when turning up for the study, causing more confusion.

⁴² The authors analyse the social meanings of research membership in Gambia and the blurred distinction between research and healthcare.

the delivery of biomedical healthcare more generally (discussed in chapter six on hepatitis).

In this regard, while the survey was rationed, in theory everybody had access to free treatment through mass drug administration that was due to be distributed in the coming months. Yet this was also an inconsistent event and therefore not a guarantee of access to treatment, (discussed in chapter four). Furthermore, many expressed medical testing as a need or a right. A few expressed dissatisfaction with mass drug administration because they took drugs without knowing if they had the disease or not. People stressed the importance of testing in order “to know your status”, a phrase that echoes messages from HIV programmes. Access to treatment through mass drug administration was one aspect of biomedicine. Access to testing and knowledge was equally important.

In addition, some participants expressed frustrations towards the results of the survey. In the study we were investigating schistosomiasis and other soil-transmitted helminths⁴³. When told their stool sample was negative, some people questioned the results. *How can we be negative when we have symptoms?*, was a common question at a number of the sites. Some went on to question the validity of the findings and the reliability of the equipment. *Is the equipment out of date? Does the microscope really work?* This mistrust was in part because people had abdominal symptoms. Additionally, the findings were at odds with what people knew: along the river they must have bilharzia. In these situations, we advised people to attend the health centre for further management. Yet this survey was their hope of getting definitive answers, and once again, they were told there was nothing else that could be done here, they must go elsewhere. Frustrations

⁴³ The kato katz with malachite green method makes it easier to detect these helminths but not other eggs or cysts.

towards the perceivably arbitrary sampling of deciding who and how many people participated, and the lack of definitive answers once tested, echoed people's frustrations towards the provision of biomedical healthcare⁴⁴.

The response to the survey as a biomedical health programme also demonstrated dynamics of power in participating in healthcare programmes. People's engagement in the research was demonstrably important for one local leader in particular. When signing the visitor's book at the end of the survey, I read the previous comments. Recent visits had been made by healthcare personnel for immunisation programmes and health education activities. A number of times in the comments section it was written that people's attendance had been low and engagement in the programme poor. Indeed, some local authorities suggested to me that this area had a reputation for being 'hard to reach'. This was not meant solely geographically, but it reflected a perception that these people did not engage in health promotion activities. The local leader was keen to demonstrate otherwise, he was keen that they were represented well in the research. Having sampled fifty of the adult population the previous week, following the stool testing he asked to see which people hadn't re-attended so that they would not be put forward for subsequent activities like this. In fact, only two people had not re-attended (i.e. 96% follow-up rate) because they were out of the area; a high follow-up rate.

The research programme was part of a repertoire of healthcare, and participation in it a demonstration of people's right to healthcare (discussed in subsequent chapters). Taking a purely epidemiological approach proved to be more difficult

⁴⁴ Whyte (1997) analysed the uncertainties of biomedicine in relation to HIV in eastern Uganda in the 1990's. She demonstrated that these institutional failings of biomedicine encourage people to turn to alternative forms of healing and healthcare. This is reflected in discussions in chapter's five and six on Buruli ulcer and hepatitis B.

than anticipated in a research protocol. It left aside the biosocial process of research for those participating (both researchers and researched). Turning the social analysis to the process of informed consent illuminates similar complexities.

INFORMED CONSENT

While biomedicine is a form of power and knowledge, Kelly (2003) argues that informed consent is a way to “remedy an imbalance of knowledge and power by constructing its subject as a “citizen”” (p.183). However, she argues this bioethical process restricts ethnography through its focus on protocols, rather than “the everyday of personal aspects of moral reasoning” in anthropology (ibid. p.183). With research on health matters, including anthropological or social science research, the field of bioethics dominates the formal processes of ethics in research.

There have been some notable trials that have forced ethical debates on the experimental nature of biomedicine⁴⁵ or the nature of informed consent⁴⁶. Reflected also in the Association of Social Anthropologist’s ethical guidelines⁴⁷, there has been an increasing anthropological enquiry into ethics in practice, including the nature in which ethical principles such as informed consent are applied, and the relational dimension of informed consent as an ongoing process (Harper and Jiménez 2005, Harper, 2007; Geissler and Molyneux 2011). In this respect, the discussion here provides a further ethnographic example of ethics in practice.

⁴⁵ For example the ‘Tuskergee Study of Untreated Syphilis in the Negro Male’ in the United States between 1932 and 1972.

⁴⁶ For example the controversy that arose after Tierney published a book confronting a geneticist and anthropologist’s involvement in medical research during a measles epidemic in the Amazon in the 1960’s. Discussed in Harper, 2007.

⁴⁷ <http://www.theasa.org/ethics/guidelines.shtml>

Ethics in health research is influenced by biomedical practice and bioethics, which in turn are influenced by law and philosophy (Farmer and Campos, 2006; Harper, 2007). The idea of consent, rather than social processes and local moral reasoning, is based on “competence, information, and voluntariness” (British Medical Association Ethics Department, 2004, p.135). It is governed by substantial requirements from institutional review boards which required that informed consent is sought in all research involving humans as research participants, vulnerable people and research on medical or health related issues (UNCST, 2007). It implies moral accountability of the researchers to those participating in the research, and legal accountability to the Institutional Review Board or research authority. A number of the regulations are particularly pertinent for clinical trials and intervention studies, but the principles are applied to all health-related research. Informed consent was therefore a major feature of the epidemiological survey in Moyo and Adjumani. My purpose is not to question the need for informed consent, but to illustrate the process and application of applying these ethical principles in this setting which, like epidemiological methods, was not straightforward in practice (Dilger, 2011).

In this research, an informed consent document was required for ethical clearance. This was a substantial written document providing the details to be explained to each participant. It was written in English and then translated into a written document in the local language. This conforms with the importance for documents and information to be translated into the local language where research takes place. However, the situation was more complex. At the fishing sites in Moyo and Adjumani, many participants did not read or write; the information was explained to them in their preferred language and they provided a thumbprint to confirm consent. The participants kept a copy of the information sheet, either in Madi or

English, for future reference. The information was explained to people in their language, yet many preferred to keep a copy of the English document. If people did read, they were more likely to read English as this is the language used in school⁴⁸. Having a translated copy of the form was useful for demonstrating awareness that there were issues around language, but the quality of consent was based on the verbal communication of the information and not the mere fact of the written documentation.

Needless to say, there were concerns for these issues by the institutional review board in Uganda. During a meeting with the board, a significant part of the discussion was on disseminating the study findings to the participants and wider communities. We discussed many options on the most appropriate manner that would be accessible and understood by a population where the majority did not read and write. However, the informed consent procedure was based around a legal document guided by rigid bioethical notions with little flexibility allowed in its application.

Kelly (2003) argues that “Informed consent is a product of protocol and documentation; its legitimacy comes from outside the scientific situation. From the outset, informed consent must be understood as a problem of social control and public management.” (p.184). Certainly, for the institutional review board it was a way of monitoring our research practices. The protocol ensured that key elements were addressed such as sensitivity to language. It was a lasting documentation on what was discussed and what was agreed between the researcher and the participant. For the research staff it was a way of demonstrating this, of being

⁴⁸ Years one to four in primary school are taught in Madi, or the local language, with English taught as a subject. In following years in primary and secondary school, all lessons are taught in English with Madi/the local language taught as a subject.

accountable to the research authorities. It was a process needed for Kampala, for the Ministry, to check that we had followed the correct procedures.

For research participants, it had other meanings. For many participants, even if they could not read the information sheet, they kept the form and some brought it out when we returned for follow up visits or came to speak with people individually. It was another medical document, kept with their clinic notes from the health centres which were often written in school exercise books. As Susan Reynolds Whyte (2011) identified on the practice of writing in medical research in Uganda, for research participants these written documents were an integral part of getting healthcare, whether or not they were understood. Written documentation was significant as a sign of research participation rather than being a document of information and informed consent.

However, specific information on the form was valued. Included on the information sheet were my mobile phone numbers in case people needed to contact with questions about the research. At one site, a few young fishermen in their twenties challenged me afterwards about this information on the form. In English, one said: *"If we have a problem with sickness here and we ring you, what will you do?"*, *'What will happen when you finish and go back to England? How will we contact you there if we have a problem with our health here?'* In asking these questions, I believe he was also trying to understand what the research relationship meant both now and in the future. In doing so, he and others challenged research programmes, how they addressed their needs through short-term projects.

Not only was research participation a route to access immediate, short-term biomedical healthcare, it was also a route to health authorities. For some, I was perceived as being somebody who could liaise with the authorities and therefore a

channel to have a voice. While one fisherman questioned if I really did have this ability as I always came to the fishing site without the district officials, on a number of occasions I was asked to relay messages to the sub-county or district authorities. A lot of the requests and concerns were often related to the structural constraints people faced and were beyond the capabilities of one researcher. For the young fisherman quoted above, it was known that the link would be severed at the end of the research. This was only a further frustration. For these fishermen, their concerns went beyond the one-off provision of testing (something tangible that was offered to the research participants). As was demonstrated in the discussion on epidemiological methods and will be further demonstrated in the following chapter, health was largely a social and political matter as well as an individual, biological one. Furthermore, the ambiguity of biomedicine, research and researchers was also reflected in my own position as an interdisciplinary researcher.

BEING INTERDISCIPLINARY

The final methodological reflections are on being an interdisciplinary researcher both in conducting the research and in writing up. I discuss some of the personal-professional dilemmas I faced. I found myself, as Harper writes, “in complex situations at the borderland of medical and public health practice” (2007, p.2245). The following is an account of the initial stages of fieldwork, of making sense of what I found around me and my place in it. I reflect on how it influenced my role as a researcher, as well as people’s response to me. Finally, I discuss the process of writing up, analysis and presenting the research.

Having arrived in Adjumani, I spent the first two months making introductions at the district authorities and at the sub-counties along the River Nile in both districts.

With a local researcher, we visited various landing sites and talked with fishermen and fishmongers, Local Chairmen (LC 1) and Beach Management Unit members (BMU). We also visited the health centres nearest the landing sites, health centres that served each sub-county, and private clinics in Adjumani town. Once a week I attended Adjumani Hospital. I visited the medical ward and outpatient clinics, spending time with the nursing staff, clinical officers, a medical student from Kampala on his medical elective, and doctors. The hospital medical superintendent gave permission for me to sit in on clinics and ward rounds. This experience allowed me to begin to understand some of the constraints that the public health service was working under, the relationship between the public and private sectors, the medical conditions seen and how they are managed.

In doing this I found myself struggling with my position in the field. Prior to fieldwork, I had prepared myself that I was going as a researcher. I was not there to practice clinical medicine, and while in Uganda I revoked my licence to practice in the UK. However, I was concerned that I might need to act as a 'good samaritan' while out in the field. For my own confidence and peace of mind I updated my 'Immediate Life Support' training in the UK before leaving for Uganda, although I knew that the setting would be different with no publicly located automated defibrillators or a fast response from a 'call for help' with a limited ambulance service.

While out and about I did come across a couple of trauma incidents. On one journey from Kampala to Adjumani, a male pedestrian had been hit by a fast-moving heavy goods vehicle and had suffered obviously severe injuries. We arrived as the police, there being no ambulance service, were putting him in the open back of a pick-up truck (a rudimentary 'scoop and run' technique) to take him to the

nearest hospital a number of kilometres away. He was unlikely to survive. The image haunted me.

A few weeks later, when on our way to a fishing site to carry out the parasitological survey, we came across a man lying in the road. I made us stop and assess if the man was alive or dead, despite the insistence that it was the police to deal with these matters. (It wasn't as bad as it first seemed, the man came to but had what later turned out to be only soft tissue injuries from having been beaten. People around had initially been reluctant to intervene.) At first I couldn't understand their indifference. Apparently he had been there overnight and when we asked passers-by, some said 'perhaps he is dead', and others 'perhaps he is drunk', and carried on walking. We later found out that the wife, who had beaten him the night before when they were both drunk, had been accused of witchcraft. This probably explained some of the indifference and reluctance to intervene, but shortly a large group of people arrived and brought the woman who had been accused. Some of the people who had now gathered started to become aggressive towards the woman and after some time it was clear that the police could not attend. They were out on another call in the only police vehicle that had fuel. We took him to hospital to be checked over. It was seen by some as over the top to intervene, but my reasons were in part from a professional 'duty of care' to stop and assess, and in part because the previous experience had stayed with me.

Many of the points illustrated in this vignette are picked up on throughout the thesis (access to biomedical healthcare and emergency services, the constraints on these services, and understandings of witchcraft), but the point I want to make in this section is that my role as a passive observer was sometimes challenged. In this sense I was engaging in participatory observation, even if all I did was to assess if someone was alive or dead or offer a lift to the health centre or hospital.

A number of times people asked for advice about non-specific symptoms. Under the circumstances and as per guidance⁴⁹, the advice I could give was to attend the nearest health centre. On occasion, when we travelled by car (the vast majority of the time we travelled on motorbike, we used a car in the final two months during the rainy season) I took a young girl with a skin disease and a man with untreated leprosy to a higher grade health centre which was further away in order that they might get the necessary diagnosis and treatment.

The more challenging encounters actually occurred in the hospital, where I least expected it. It was here that I found I had to repeatedly reinforce my position as a researcher and not a clinician. While simple in theory and clear in my mind, it could be uncomfortable in practice and I was often left with a feeling of being helpless. On one day, I had been sat in the outpatient clinic with one of the clinical officers. A male boda-boda (motorbike taxi) driver and his passengers, a woman and her young child, had been rushed in having been involved in an accident. The child was relatively unhurt, but the two adults had deep wounds that needed stitches. The clinical officer⁵⁰ went to the minor surgery unit but nobody was available. Two nurses had cleaned the wounds and were preparing the sterile equipment for stitching. As there were two patients, the clinical officer suggested that we each saw one and did the stitching. I had to explain that I wasn't able to, I wasn't licenced to carry out this sort of procedure. While professional ethics guided my response, it felt awkward being there observing but not participating, not helping a colleague. In the meantime, he stitched up the patients' wounds one by one, provided them with antibiotics and they went along their way.

⁴⁹ General Medical Council, Good Research Practice; Ethical clearance guidance.

⁵⁰ Equivalent to Medical Assistants, in order to fill a gap in medical personnel in the public healthcare system, clinical officers undergo three years of specialist training before being employed in the national healthcare system (in outpatient clinics and on hospital wards). See Banerjee et al, 2005.

On this occasion, and many others, I was left with uncomfortable questions on my own expectations (as a researcher) and the expectations of others (trained as a doctor), observing but not participating. Having a medical background meant that at many times these encounters and observations made me uncomfortable with my position as a researcher and observer, yet known by others to be trained as a doctor. As described, this was particularly the case in the hospital.

Yet on the other hand, having arrived in a new place where I was to stay for a year, the familiarities in the hospital were reassuring for me. The biomedical language, structure and turns of phrases written in the clinical case notes were of a universal language, familiar to me in a setting far removed from my experiences of hospital medicine in the UK. However, the realities of practicing medicine were vastly different. This was not only in the conditions seen but in the management strategies available. Observing these actions, or often inactions due to an inability to act, was challenging but also demonstrated the constraints on public healthcare in this setting.

These encounters occurred on a day to day basis in the hospital. For instance, there was an inability to perform liver function tests on somebody with hepatitis because these blood tests were not available. There was an inability to give a blood transfusion to somebody who was severely anaemic because there wasn't the matching blood group available. Drug resistant tuberculosis patients were treated on an open ward because there was no isolation unit. I greatly admired the clinical staff, their clinical skills and the way they made decisions under these less than ideal circumstances. The investigations requested and treatments prescribed were not always available, but they were still discussed by the doctor and written in the notes as an ideal, as best practice.

Being in the field as a researcher, the fact that I had training in medicine inevitably shaped the research. It made me see these practices in particular ways and it shaped my response to what I saw. It also shaped people's response to me. I am therefore aware of the fact that my position was perceived in a particular way by those I spoke with, and this may shape my findings. However, returning to the area since 2009, and carrying out the current ethnographic fieldwork over a long period of time (during which time we shared time, food and many conversations at the landing sites), allowed relations to be built with people that went beyond the fact that I had been involved in a biomedical survey on intestinal worms. People saw that I was interested in the broader aspects related to health. When talking with local healers, we had a common ground in our interests in health, illness and healing.

On the one hand, I did not learn the Madi language fluently in order to converse comfortably alone; on the other hand, I knew the biomedical language and customs. Being in the field away from my usual biomedical experience enabled me to see the practice of biomedicine as an observer. Having the biomedical background enriched my understandings. It enabled me to not only discuss many diseases and illnesses with people, but to discuss technical aspects with the district and health staff (see also Harper, 2007).

However, on my return I continued to struggle with some aspects of this interdisciplinarity. I found myself grappling with how to present my findings and the process of writing up took some time. One of the difficulties stemmed from epistemology, in combining the different approaches of analysing and objectifying the research experiences. While my fieldwork was very much guided by an ethnographic approach (even the epidemiological component), when writing I struggled with trying to present an objective account of both biological and social

'facts'. It was particularly hard to find my voice, to find the right approach to present the epidemiological and ethnographic data woven together. I originally addressed the biomedical 'facts' on the diseases and then tried to situate the ethnographic details into social theory. Neither approach was satisfactory with each objectifying people's subjective experiences of life, health, sickness and death.

This thesis is therefore written from a middle ground, neither strictly epidemiological, nor framed within abstract theoretical concepts. The following four chapters describe what I learnt about people's experiences in relation to life, disease and healthcare along the river in the districts. While this has been a confessional tale of my experiences of fieldwork, in the chapters on the diseases, having provided a background on the biomedical paradigms of disease and public health, I present people's words of their experiences and understandings of illness and healthcare. I do not want to reinforce an illness-disease dichotomy, as Kleinman cautions against (2013). I present the material in this way in order to present people's voices as individuals as well as their collective experiences of public health concerns.

CONCLUSION: RESEARCHING NEGLECTED DISEASES

Having outlined the methods used, this chapter has demonstrated some of the insights and tensions that an interdisciplinary approach to the research brought. These are as Inhorn and Wentzell describe, "productive tensions" (2012 p.5).

The tensions that have been described from this fieldwork in part stem from the different methodological approaches of a biomedical, epidemiological and ethnographic study of health, disease and illness. In part they also arise from divergences between global and local perspectives on the practices and realities of conducting research. These two areas where tensions arise are intrinsically linked

whereby global health has emerged from a history of biomedical approaches to disease and technical fixes to manage them, alongside an increasing critique on the application of these norms and the interventions that stem from them within local contexts. Biomedical and ethnographic approaches used together have illuminated a deeper and broader understanding of complex situations of health, illness and healing (Inhorn and Wentzell, 2012, p.2). This interdisciplinary approach is what led to the development of interest in the broader concept of neglect and neglected diseases that this thesis engages in.

In taking an interdisciplinary approach in this PhD research on neglected diseases, an epidemiological study was incorporated into the study in order to try and estimate the burden of schistosomiasis among fisherfolk in this region. The ethnographic approach however was essential for the findings of the study for a number of reasons. This was firstly by asking and seeking to answer, 'why has a public health programme worked in this area and not others?' as addressed in chapter four on schistosomiasis control. In addition, the flexible and inductive approach enabled the exploration of the biosocial context of neglected tropical diseases. This was not only the social, economic, historical and political context as described in the following chapter. The context also included the investigation of other diseases, Buruli ulcer and Hepatitis B, diseases which have important stories in the districts which would otherwise have been put aside.

The following chapter provides a background, illustrating both the historical and contemporary features of neglect and marginalisation in this area of Uganda. It describes fishing livelihoods and fisherfolk's relationships with authority, be it fisheries or public health. It therefore engages in the social, economic and political features of the lives of people affected by neglected diseases.

3. 'MERI TI BA': MAKING A LIVING ALONG THE RIVER

On International Women's Day, 8th March 2014, Moyo District held its official celebrations in Obongi town along the River Nile. Hassan Fungaroo, the MP for Obongi and member of the opposition party, Forum for Democratic Change (FDC), gave a speech. He opened by saying:

'If women in Uganda have two problems, women in Moyo District have four. And if women in Moyo District have four problems, women in Obongi have eight.'

He went on to discuss some of the difficulties people of Obongi faced with respect to health and healthcare. This day was also the day when a new, state of the art ambulance fitted out with all the modern equipment for monitoring and providing emergency care in the back was brought for the county to be stationed at Obongi health centre IV. The writing on the ambulance read: 'Obongi self-help AMBULANCE', 'Purchased by The PEOPLE AND FRIENDS of OBONGI COUNTY'⁵¹. It was an achievement for many, symbolising the political voice of people of Obongi. There was a feeling that Obongi had been neglected, cut off, and some even wanted it to become a new district. With a ferry crossing opened from Adjumani in 2012, and now the arrival of the ambulance, it was a sign of beginnings of change.

The ambulance itself was quite striking in contrast to its predecessors. Ambulances in Moyo and Adjumani were typically double cabin pick-up vehicles. Patients, bodies or coffins, were laid in the open back and transported to or from the district

⁵¹ Each household in the county contributed a small amount which was topped up by donations from individuals and available development funds.

hospital. Fuel was not provided. People in Obongi reported that they had to provide a twenty litre jerry can of fuel (80,000 Ugandan shillings⁵²) before being transported from the health centre IV to the hospital in Moyo town. In Moyo and Adjumani towns there were a few petrol stations, but in Obongi town petrol was sold outside small shops. A small (five to ten litre) jerry can of petrol was displayed on a stool alongside a plastic bottle cut in half to make a funnel.

The speech by the Obongi MP was in relation to women, but the sentiments were often expressed more generally. Even in the main towns, people talked about places outside the trading centres as 'deep in the village', reflecting a distance both physically and metaphorically from urban life. This was particularly the case for Obongi, where people outside often expressed fear of going there. In the past, I was told, if a public worker was transferred there it was called 'panel beating', you knew those senior were trying to get rid of you. It was thought that you would only return in a coffin. These were areas where strange happenings occurred, where witchcraft was prevalent. Indeed, the first time I arrived in Adjumani in 2009 and moved to Laropi, also along the River Nile, similar concerns were expressed over high rates of witchcraft there.

Along the river, people were referred to as '*meri ti ba*' in Madi, meaning 'people of the river'. Commenting on their ways people would sometimes remark, '*ah, ah, meri ti ba, meri ti ba*'. It was sometimes said that you cannot change their ways, for instance in their use of the river water even if there is a borehole. Sometimes the fishing sites were seen to be places which were difficult to govern, with the fishermen and women resisting the enforcement of regulations. Yet, as will be shown here, those in the fish business were also extremely hard working. Two

⁵² Equivalent to twenty GBP at the time.

officials suggested that fish-for-sex transactions occurred, although it was unclear if this came from understandings of fish landing sites along Lake Victoria or understandings of the local context. It wasn't something that featured significantly in our fieldwork. Moral authority was governed by elders and local chairman, and the nature of the fish business was on a smaller scale with less competition and other options for securing fish transactions, making it vastly different to the situation found along Lake Victoria.

The points illustrated so far about life and livelihoods along the river, are the essence of this chapter. The first point is the distanced, marginalised positioning of those along the river, and second is the everyday reality of people's lives along the river and their resistance to this positioning. This is the context in which those vulnerable to neglected tropical diseases live and work.

Fisherfolk are at greater risk for many neglected tropical diseases because of the nature of the work they do and the environmental areas that they live and work. The framing of neglected tropical diseases suggests that they suffer from these because they live and work at the margins with limited access to healthcare, with little political voice to challenge the status quo. However, health and healthcare become a way of asserting power and agency. The aim of this chapter is to set up themes for the following three chapters. The first aim is to illustrate the local context that is a key feature in all three chapters. The nature of fishing livelihoods is developed in chapter four on schistosomiasis and mass drug administration. The second aim is to show the everyday choices and decisions that people make, which is part of the analysis in chapter five on Buruli ulcer. Finally, this chapter demonstrates how people respond to neglect. This is exemplified in chapter six on hepatitis B which illustrates how people have made sense of an emerging disease.

This chapter therefore provides a background to the area where this research took place, the people who live and work along the river, and the historical, political, economic and social context that shapes their experiences of health, illness and healthcare. Indeed, this area of Uganda has historically experienced political and economic marginalisation. Yet this chapter also shows where people resist, where they exert their agency politically and economically. Despite neglected tropical diseases being defined by the social, economic and political situation of the people that they affect, defined by neglect and marginalisation, little is written about these factors. This chapter seeks to re-balance this, focusing on the life and livelihoods of those vulnerable to neglected tropical diseases.

The chapter is divided into three main parts. It begins by outlining the historical context of Moyo and Adjumani Districts. Drawing on long term fieldwork that has been carried out by anthropologists on health and illness among the Madi (see for example Allen, 1991; Allen & Storm, 2012; Parker & Allen, 2011), it provides an account of the historical, geographical, social, political and economic context of life in this area.

The second section describes contemporary life along the river. It begins with an overview of the different landing sites visited, providing localised details and demonstrating some of the similarities and differences. It then looks at fishing livelihoods and aspects of the local economy. It also demonstrates how fisherfolk resist governance and in doing so where they have political voice. The chapter concludes by reflecting on local discourses of development and human rights. In this region where people have experienced social upheaval, health and healthcare are asserted as a right.

MOYO AND ADJUMANI DISTRICTS: SOCIAL UPHEAVAL AND HEALING⁵³

The people of Moyo and Adjumani districts are predominantly Madi. This name is likely to come from the word in the vernacular for a person, *ma'di*. Rather than one homogenous group, the Madi descend from a group of clans who, according to oral history, migrated many generations ago from the north (southern Sudan) to the western and then eastern banks of the River Nile in the now border area of Uganda and South Sudan. There are some similarities with the neighbouring Lugbara group in West Nile; the two languages are similar along with some of their customs. John Middleton wrote extensively on the Lugbara following fieldwork in the 1950's. Yet before Tim Allen's work in the 1980's and 1990's, there was little detailed writing on the Madi. There is even less written on Obongi County. As Middleton wrote, following a brief time with the Madi in the 1950's: "Between the northern and southern Madi are several small enclaves of Kakwa and Kuku (Reli, Obongi, Gimara, etc). The whole of this area is ethnically extremely confused." (1955, p.30). During fieldwork, a fisherman speaking in English once described Obongi to me as "*a cosmopolitan county, with many tribes*". In contrast to most of Moyo and Adjumani, people in Obongi County are predominantly from Lugbara or Kakwa related groups (Aringa, Aliba, Reli, Gimara for instance).

The area has experienced much social upheaval (Allen, 1994; Allen, 1996; Allen & Reid, 2015). From the 1860's, ivory and slave traders were operating in the area and it was occupied by Turco-Egyptian forces. At the beginning of the twentieth century West Nile (as the area of northwestern Uganda is often known) was under Belgian rule along with the Congo. In the early twentieth century it became administered under British rule as part of the Ugandan protectorate. During this period, Moyo and Adjumani as they are today were administered as Madi Sub-

⁵³ This section draws on work by Tim Allen including: Allen 1994; Allen and Storm 2012.

District under Nimule (now in South Sudan) and Gulu (in Uganda). It became its own district, Moyo, just before Uganda's independence in 1962. At that time, East Moyo (now Adjumani) and Obongi were two counties within Moyo district.

In 1971⁵⁴, Idi Amin who was originally from West Nile overthrew Milton Obote's presidency. By the end of Amin's regime in 1979 when Tanzanian and exiled Ugandan forces overthrew him, those living in the West Nile region including the Madi were perceived to have been sympathisers. During ensuing conflict in the 1980's at the time of Obote's second presidency (1980 to 1985), the majority of people in both Moyo and Adjumani districts fled into neighbouring countries, in particular to southern Sudan. Those from Obongi County either fled to southern Sudan or Zaire, as the Democratic Republic of Congo was then.

This period spent as refugees was known as 'exile' and is a significant event in the social history of people in Moyo and Adjumani districts. When working out dates, for example of schooling, marriage, or sickness, a reference point was often 'exile': before, during or after exile.

During this period, some people remained in Uganda. Others found life in exile difficult (with little food or land for agriculture) and returned to the districts earlier. One fisherman described how for four years he remained in the river, hiding on the islands or in the reeds and only coming to land once in a while to exchange fish for salt and flour. People found means to survive, as one woman explained of her family:

We didn't go into exile. When there were problems here we would cross to [the other side of the river] – this happened one time. There was no assistance provided for those who remained here. When we were here, the

⁵⁴ For a political history see P. Mutibwa, *Uganda Since Independence: A story of unfulfilled hopes*.

Liberation Army were disturbing us and we would hide ourselves. There were no schools and no health centre during that time. If you are sick, you would look for local herbs. Very few people remained. My father was a brave man and didn't want to go away. During that time, we were cultivating and fishing here. My father had cattle, goats and chickens; that's how he could survive. When the Liberation Army came, they would take chicken, or fish. If they killed him, they would stop getting his help in providing this food. The soldiers would eat it, because they knew there was no poison in it as it had been prepared for the home. [Female fishmonger; 37 years old; interviewed 29.01.2014]

The home of this woman was along the river and they could flee across to the other side if needs be. Families also stayed at their homes if they were near army detachments, often away from the river. The following extract is from an interview with an elder and clan leader:

Those here around the prison where the army was stationed, they didn't go to Sudan as refugees. The government (Obote II) soldiers knew them as they had lived around them, therefore they knew they weren't rebels and therefore didn't disturb them. If they didn't know your face, they would say you were a rebel and kill you. Beyond here, nobody stayed, until you reach [name] where another army detach was.

The rebels from Sudan would sneak back and disturb here, taking cattle. Anyone who remained was seen as an enemy by the rebels. There was no soap or salt in the markets here in Adjumani, so they would have to go to Sudan, Nimule, to buy items there. But there you would have to hide as you were seen as enemy of the rebels, reporting on them. Those who remained here were enemies of the rebels. Those who fled to Sudan were enemies of

the government soldiers. [Mzee; clan leader; interviewed in English, 16.11.2013]

These final points illustrate the ambiguous state that people were living in in this area at the time, whether along the river, by the army detachments or in exile. The majority of those who had fled to southern Sudan returned from 1986 following attacks on the refugee camps by the SPLA (Sudan People's Liberation Army) (Allen, 1996). By this time, Yoweri Museveni had taken power in Uganda with his National Resistance Army. Other opposition groups continued to operate in the region, including the West Nile Bank Front to the west (on Moyo side) and the Holy Spirit Movement in Gulu to the east (Allen & Reid, 2015). Tim Allen (1994) conducted fieldwork in Moyo during the time when people returned from exile in Sudan. At this time, Allen writes, people found themselves in an area which had been devastated by the violence. Homes, health centres and schools had been destroyed. Health services were run in Moyo and Adjumani towns by Médecin sans Frontières (MSF) who were also managing a sleeping sickness outbreak.

In the late 1980's and 1990's, conflict in southern Sudan led many Sudanese to flee to both Moyo and Adjumani districts. Humanitarian relief continued and schools and health centres were built (sometimes jointly under the United Nations and Ugandan Ministry of Health) in refugee areas to provide extra infrastructure. Later in the 1990's and 2000's, from the Holy Spirit Movement emerged Joseph Kony's Lord's Resistance Army (LRA) which was active in northern Uganda (Allen, 2006). Predominantly attacking areas in Gulu District, the LRA also raided villages in Adjumani District and in some areas people were internally displaced from their homes. While the LRA did not cross into Moyo District, both districts were relatively cut off during this period as travelling along the main roads was

particularly dangerous. With risks of attack, all travel from Gulu to Adjumani was within a military convoy.

In making sense of the violence, uncertainties and social upheavals that had occurred over many decades, during the late 1980's and early 1990's the social responses were at times violent. People, often women, accused of being a witch (*ole*) were violently attacked and even killed (Allen & Reid, 2015). Allen interpreted these acts of seeking social accountability as a form of social healing (ibid.). As the authors explain, this was a time when forms of authority were being re-established through the elders whose authority had been undermined during the Protectorate and exile periods. Alongside this, new forms of public authority were established through Resistance Councils (instigated by Museveni) that later became the directly elected Local Councils, the system which continues today.

Interpersonal causes of affliction were common, particularly for unexplained illnesses or deaths. As explained by Allen and Reid, when witchcraft (one form being *awola*) was suspected to be the cause of an affliction, people sought out witchdoctors (*oja*) (often women) as spirit mediums who performed rituals. In some cases, accusations would be made about who was inflicting the witchcraft. Other forms of poisoning were common, including *inyinya*, which was reported to be obtained from snake venom. It was also during this time that HIV/AIDS became known about, understandings of which were shaped by these understandings of witchcraft and poisoning (ibid.).

The Catholic Church has been influential among the Madi, and more recently there has been a rise in Pentecostal Churches and people becoming 'Born Agains'. Witchcraft, seen as satanic, appears to have reduced or at least the methods for dealing with those accused have taken on a democratic form (Allen and Reid, 2015).

Despite this, forms of poisoning are still a concern for people and in fact other forms of witchcraft are becoming increasingly so.

Abiba, 'people (*ba*) in the wall (*abi*)', was one such pressing concern during 2013 and 2014. A person accused of having abiba reportedly wakens the dead from their graves and keeps them in the walls of his house. In the night, he sets them to work in his fields, or to carry luggage for his business for instance. People reported seeing red lights at night, a sign of abiba working. Sometimes it was explained that the person with abiba caused the deaths of people, for instance through a bus accident. At funerals, abiba was suspected to be working if strange things happened, such as a sudden wind that forced people to take shelter. At this point, it was said, the person with abiba took the body from the grave. Nobody dared re-open the grave, but it was said that if you did the body would be gone.

Suspicious were raised about somebody if they had large pots cooking on the fire when there are only a few people at home – supposedly to feed the people in the wall. They were also raised if somebody had a good field of crops while other people's crops were not thriving. Antidotes (a small piece of skin of a particular wild animal) could be carried to prevent somebody afflicting abiba on you. Unlike other forms of witchcraft, those suspected of abiba were rarely openly accused or confronted for fear that they would afflict you (you would die to then work for them). At one fishing site, people reported that abiba was active as many red lights had been seen. They had called a witchdoctor who performed rituals to cleanse the area, but not to directly confront anybody.

In 2014, a young woman who had not been seen for years and had reportedly died, was found walking along the side of a road in Adjumani. She reported that she had been taken by abiba and made to carry luggage at night from South Sudan to Kampala for a businessman. Some people feared to go near her, but she was

brought to the local Catholic Church in Adjumani for safety and later taken to the police station. It caused a stir, with many people going to the Church to see and hear the woman. Some people I spoke to saw this as a sign that abiba was really working. However, some were unsure, especially when it was later reported that the woman had a history of mental illness. One woman I spoke to refuted it from the beginning, it couldn't be true that someone who had been buried was brought back to life.

Abiba has also been described by Leonardi et al (2010) in Kajo Keji, across the border from Moyo in South Sudan. Here, they report it to have been brought from Uganda, having returned from refugee camps "with the perception of new dangers hidden within the community" (p.57). For many people in Moyo and Adjumani, abiba was something to be wary about. As a form of witchcraft, abiba was a way of explaining and expressing concern over the success of others in agriculture or business and their individual accumulation of wealth and development.

CONTEMPORARY LIFE ALONG THE RIVER

Since 2006 / 2007, life has been relatively peaceful and stable in Moyo and Adjumani districts. By 2013, some people who were displaced in the 2000's had begun returning to their land, but others were reluctant to while Kony and the LRA were still operational elsewhere in Central Africa. Others had built their houses and homes in new areas and continued to live and work where they had settled.

In recent years, new sub-counties had been created in Adjumani with ongoing establishment of new sub-county headquarters. Along with this, there was a process of upgrading health centres. Different grades of health centre offered different levels of service. Health centre II's (at the Parish level of administration, these health centres do not have laboratory facilities) were being upgraded to

health centre III's (at the sub-county level of administration, these health centres do have laboratory facilities). In this system, the Village Health Team (VHT) (those responsible for distributing the mass drug administration) acts as the health centre I. One or two people from within the village are given basic training for mass drug administration and oral anti-malarial treatment. Across the board there is a shortage of health care staff of all professions (discussions with district and health staff).

Some aspects of life have changed, both since the period of fieldwork in 2009 and even during fieldwork over 2013 and 2014. Travelling to the districts is becoming easier, with more bus routes travelling to Moyo via Adjumani. North of Gulu town in northern Uganda to Adjumani and Moyo, the roads are marred and often in the rainy season buses break down or get stuck. However, over 2013 and 2014 Chinese contractors were in the process of constructing the road between Gulu, Atiak and Pabbo to connect to Nimule and South Sudan, bypassing Adjumani and Moyo. Many vehicles (lorries, fuel tankers, local buses and national coaches) passed this route from Gulu to Juba in South Sudan. From Nimule to Juba the road is tarmacked and in fact from Adjumani it was quicker to reach Juba (a two hour drive) than Gulu (anywhere between two and a half to four hours, one time it took six hours in the rainy season). Juba was a town where many hoped to find work. The wages were higher and life was perceived to be better there with more opportunities for work, including employment with non-governmental organisations.

Transport within the districts was also easier, with more local buses travelling between the two towns and Arua. The route between Adjumani and Obongi on to Arua was also becoming more popular with the opening of a Uganda National Roads Authority Ferry at Sinyanya-Obongi in 2012. There was still no public

transport means between Obongi town and Moyo town. In addition, in 2013 Adjumani town was connected to the national grid electricity, although only some homes and buildings were connected. By the time I left, they were about to cross the electricity line over the Nile to Laropi and on to Moyo town. There were no moves to connect the electricity to Obongi.

Adjumani and Moyo districts have suffered much upheaval over the last two centuries and it is only relatively recently that people are readjusting to a time of peace. Upheaval still occurs in the region. South Sudan has suffered ongoing conflict and many South Sudanese have fled into Adjumani district since the end of 2013. Following this protracted period of uncertainty and upheaval there have been some developments in the last few years in particular. While much has changed, many places including many of the fishing sites along the river remain far from the developments that are happening in the main towns and along the main roads.

FISHING SITES

It was in this context that I carried out fieldwork along the River Nile. This was predominantly at twelve fishing sites spread across the sub-counties along the river. Six were in the southern aspects of both districts: Aliba Bitu, Rupo, Asamvu and Idijo in Obongi County, along with Maaji and Onikwe in Adjumani district. Six were in the northern aspects towards the border with South Sudan: Congo, Keli kwe si monzo, Lakaito, Asejo, Liri, and Onorio's Place. In the following chapters, I draw on material from all the sites and, in order to preserve some anonymity, I do not necessarily name the site which is being discussed. The reason for spending time on each individual site here is to demonstrate that while there are similarities, there are in fact significant differences between the sites. One has an 'urbanising' culture, while another is a homestead. Some were purely for fishing; others were

spaces used for mixed fishing, agriculture and livestock grazing. At some sites, women had a more prominent role in the fish business than at others.

The first sites discussed are those in Obongi County, described in the introduction to this chapter. The road from Obongi town to Moyo travels parallel to the river Nile. The majority of the area is bush or forest. At one point, the road crosses a river. In the 1980's and 1990's there wasn't a bridge at this point and one researcher recalled how they would pay people locally to carry their motorbikes across while wading through themselves. Now there is a bridge, but in the rainy season after a heavy downpour, the river breaks its banks and floods a 100 metre stretch of the road through which low-vehicles cannot pass.

Aliba Bitu, in Aliba sub-county is at the extreme end of Moyo district that borders Rhino Camp in Arua District. *Bitu* means 'side' in Madi; that is, the Aliba side of Moyo. It was explained to me that the landing site was opened in 1962 by Alur (people from Nebbi District in West Nile), who had travelled along the river. The people are predominantly Lugbara and Aringa⁵⁵ and the majority are Muslim. People's lineage is predominantly from other areas in West Nile such as Arua and Yumbe rather than Moyo. As is illustrated in chapter six on hepatitis, for matters regarding the family, clan, ancestors and witchcraft, families seek advice from relatives and healers or witchdoctors in Yumbe and Arua. Likewise, for biomedical matters, they tend to seek second opinions and higher level services from Arua rather than Moyo. This is also due to difficulties in accessing healthcare in Moyo town. While the road from Moyo to Obongi town had greatly improved, this did not extend to Aliba Bitu. With the ferry crossing at Obongi, transport can now be found from the town to Adjumani or Arua. However, Aliba Bitu is not served on this

⁵⁵ From those surveyed: 49% and 36% respectively.

route and there are vehicles that pass to Arua directly. Therefore it is easier for people in Aliba Bitu to travel to Arua for further hospital care, rather than to Moyo.

With about 400 family heads it was not an urban area but it was the largest fishing site out of those discussed here. It was the busiest site, and many young men fished in groups. They were influenced by fashions from Arua town, wearing skinny, low-waisted jeans and chewing marungi (Khat) brought from Yumbe twice a week by a man on his motorbike. There were a number of shops selling items such as cigarettes, sweets, soap, sugar, flour, and some provided phone charging facilities from solar panels. At a 'video hall', films and football matches were shown. There was a market area under a large tree, and a 'hotel', a bistro, where hot food is prepared every day by two or three women. Women rarely eat at the 'hotel', unless they are visiting for the market or passing through from Obongi to Arua. There is a mosque in the centre, a primary school on the outskirts of the village and a health centre II a few kilometres away.

The borehole was often reported to be broken. Many people collected water from the river at the fish landing site, especially as the centre is directly by the river and the fish landing site. The landing site has a permanent store building attached to a sheltered fish cleaning area. People at the landing site had constructed a wooden shelf structure for sun drying fish. Behind a wall of reeds, a small channel leads to another mooring site for canoes hidden from view.

Rupo and Asamvu are in Gimara sub-county. Along the Moyo-Obongi road is a small centre with a health centre II and two temporary shelters made out of wood – one is a 'hotel' (bistro), the other sells a few items. Two tracks diverge and branch off down towards the river from behind the bistro: one to Rupo the other to Asamvu, both about three kilometres away.

Part of the track to Rupo has been eroded by years of rain and large crevices have opened up in the road. After heavy rains, Asamvu was even more difficult to reach than Rupo, with the clay soil becoming difficult to pass by vehicle. On one visit, following a night of rain, we waited three hours in the shade of a leafless tree while the morning sun broke through and dried the earth. By the end of fieldwork the track had been widened and improved by contractors building a latrine in Asamvu who had travelled back and forth in a truck. Prior to this, in the rainy season many would travel to Rupo first, and then cross on foot across the grazing land (two to three kilometres), or take a rowed canoe and travel downstream. This is what we did on our first visit to Asamvu in 2013, taking thirty minutes to travel there, and an hour on the return journey upstream.

For people in Asamvu and Rupo, accessing healthcare and schools were major concerns. When somebody was seriously sick, the journey to the health centre on the main road was difficult. Travel on to Moyo or Obongi was also unpredictable as there are no buses or taxis along this route and therefore no guaranteed transport. There are no schools within the villages; the nearest primary school is along the Obongi-Moyo road. Therefore, many children did not attend school, especially young children and particularly during the rainy season.

I had visited Asamvu and Rupo during fieldwork in 2009. At that time, Asamvu was administratively part of Rupo village. Drug distributions were organised through Rupo village and there were organizational difficulties for people from Asamvu accessing mass drug administration. However, by 2013, Asamvu had become a village in its own right and had its own distribution register and community distributor.

People originally came to Rupo for fishing, whereas at Asamvu they came for grazing cattle with fishing developing later alongside this. Rupo village is very compact around a large open space in the centre. There are a few shops and two large trees provide shelter for a local market. Women sell small amounts of foodstuffs and once a week, second hand clothes are sold. Mid-morning on Fridays, a pick-up truck arrives to take people to the large auction at the market in Obongi town. Most of the women leave earlier, making their way on foot by a path that follows the river.

Neither Asamvu nor Rupo had borehole water. At Rupo, women collected water from the water's edge at a place separate from the fish landing site. At Asamvu, they waded out into the deeper water at the edge of the flowing river. At the time of the survey, Asamvu had no latrine facilities and, apart from a few exceptions, the majority of households did not have 'local latrines' (pits dug behind the house). In Rupo, a pit latrine had been built as part of the landing site infrastructure, but large cracks had appeared shortly after and it had been closed for fear of it collapsing, therefore people went to the surrounding grassland.

Idijo landing site is under Dikiri village in Itula sub-county. Three kilometres away is a centre along the main Obongi-Moyo road with the sub-county headquarters, a health centre III, primary school, a few shops and a piped water point. At the landing site a few sparse trees provide shelter from the sun. Sometimes, a woman prepares tea and 'escort' (usually cassava, chapatti or mamdazi (doughnut)). Tall grasses surround the banks of the river, and so the river is not visible from land. Canoes made their way through a small channel between the grasses. People come and go during the morning and late afternoon, but in the middle of the day, it tends to be quiet. Women bring clothes and bed sheets to be washed, and lay them to dry across the bushes in the sun. The river in this area has created a large lagoon

(*wele*) and a large fishing ground which is shared by Idijo and Onikwe landing site, across in Adjumani district.

Maaji is one of the landing sites for Maaji Masa, the last trading centre on the road from Adjumani to Sinyanya ferry landing site (that crosses to Obongi town). A number of shops line the road, and there is a market area that draws people from near and far on Thursdays. There is a health centre II and a primary school in the centre, built when there were south Sudanese refugees settled in and around the trading centre. At the time of fieldwork, the majority of the refugees had repatriated. The area was attacked by the Lord's Resistance Army in the early 2000's.

People settled at the landing site are predominantly Lugbara who are Muslim. People first came to settle in this area after returning from exile in southern Sudan. They were searching for free land for cultivation and initially came to the west bank of the Nile in Obongi County. Some provided transport across the river to the east bank and seeing that there was land for cultivating, began settling here.

In the centre a tree provides shade, where men and young boys prepare and repair their casting nets. At this site, many fishers start from a young age, sometimes seven years old. They save money to buy their own nets. Two male fishmongers came from Adjumani Town on their motorbikes; otherwise most fishmongers were women from Maaji. There were no facilities at the landing site itself but people had constructed a shelter for shade. They collected water from a stagnant pool in the grassland next to the river. A fish cleaning area had been built, but collapsed, leaving only the foundations as a small platform. During the final stages of fieldwork, people had begun building a bricked fish smoking area. There is a communal latrine block behind the houses away from the landing site.

Onikwe is the landing site for Lori village in Ciforo sub-county, Adjumani. Along the roads around there were a number of broken culverts, which make it difficult to pass by vehicle. There is a primary school on the outskirts, and the centre itself has two small stores. Men are often sat outside one of the stores, playing cards. A woman sells tea from the other. People's homes are dispersed across a wide area.

A muddy track leads down, across communal grazing land towards the landing site. The landing site is marked by a number of large stones (*oni*) and trees (*kwe*). There is a latrine block and one grass-thatched tukul. Fishermen stay here if they have come to fish from elsewhere, otherwise, the men and women return to their homes every evening. It is a sociable site. The landing site is a few kilometres from the village, and most people arrive early in the morning and stay throughout the day. There is a borehole in the village, but at the landing site all water is collected from the river. There are two landings for canoes. One became blocked by reeds and floating grasses during fieldwork and all fishing activities moved to the other landing area. In this second area, a natural harbour has been created, and the large, flat stones that slope down into the water are used as a washing and bathing station.

The fish are cleaned on the boulders and then dried or smoked over a fire. A wooden 'kitchen' has been erected to dry utensils, pots and plates, next to a small clay fire where a woman makes tea and cooks cassava. Other women sell locally made passion fruit wine, or alcohol sachets pinned in a plastic bag to a tree for fishermen to help themselves.

Congo⁵⁶, Laropi sub-county, is a few kilometres away from Laropi trading centre where there is a health centre III and a number of private health clinics. There are very few homes directly around the landing site. It was said that the name came about as there used to be many trees in this area, much like in the Democratic Republic of Congo.

At the landing site there is a latrine block but no borehole. There are two round shelters for smoking fish. When smoking fish, the women stay overnight next to the wood-fire ovens. A papyrus shelter has also been made for the 'hotel', and women serve food and tea throughout the day. There is also a store, and a corrugated roofed shelter had been built, but the poles holding it up had collapsed one night. Now, men and women still sleep underneath the eaves of the corrugated roof when staying at the landing site.

Keli kwe si monzo is nearby in Gbalala, also Laropi sub-county. It was known to be a good place for agriculture and growing sugarcane. *Keli kwe si monzo*, translates roughly as 'food left on the mingling stick', meaning that in this area, you did not need to scrape every morsel of food from the cooking pan and utensils, as there was plenty to eat. Up on a steep hill is a health centre II and a primary school. There are many homes around the landing site. There is a borehole at the landing site, and a nearby latrine block. There is a small shop at a clearing, and a house where a woman prepares hot food and tea where fishermen rest having returned from the river. A track leads down to the landing site. After heavy rain, the water levels rise dramatically and the track floods. There is one female fisher at this site, probably the only one in the district. She had initially been fishmongering, but

⁵⁶ In Madi it technically would be written with a 'K' to represent the hard C, but many now write it with a C, as in the country of Congo.

there is little profit in this and so she thought ‘why should I pay the fishermen and give them the profit?’ She rented a canoe and fishing gear and learnt to fish.

Lakaito is one of the landing sites for Arra village, near Omi ferry site in Adjumani that crosses to Laropi in Moyo. There is a health centre II and a primary school in the village. At the time of fieldwork, a cabin had been built by the health centre as part of the Northern Uganda Social Action Fund. Although it was not open at the time, it was to provide internet and computer facilities. There is a borehole in the village near the school, but it was often broken and some preferred the soft river water, which was collected from a separate site to the fish landing site (apart from the female fishmongers who collected water from the fish landing site).

Most people at the landing site came from Arra. The women were often washing clothes while they waited for the fishermen to return. There were long term ebbs and flows of people at the site. Female fishmongers come for a week and then travelled to sell their smoked fish at market, while others returned to the landing site to buy. There was another large fishing ground and landing site under Arra, although further away from the centre. The fishermen and fishmongers switched between the sites depending on the fish catch at the different fishing grounds.

Asejo, Dzaipi sub-county, is a landing site not directly attached to a village. The nearest villages were about seven kilometres away. The surrounding area is grassland and trees. There is a store for fishing gear, and a number of people have constructed houses. Some fishermen stayed here temporarily or semi-permanently, while female fishmongers tended to come and go daily, or stay for a few days or weeks at a time. A few women prepared tea and hot food for the fishermen when they arrived back from the river. The fishermen and women didn’t come with their families; the site was for fishing. Some women came during the

day to sell alcohol and flour. Having returned from checking their fishing nets in the morning, the men 'take tea' and food and some settled down together under a tree, drinking alcohol and chatting.

There was a latrine block but no borehole. From December 2013, a refugee settlement was situated a number of kilometres away from Asejo. Water was pumped from the river at Asejo and transported by tanker to the refugee settlements. A pump had been set up and a tap installed which the people of Asejo then used for their own domestic water.

Liri is a compact fish landing site situated between two villages in Arinyapi sub-county. It is near the South Sudan border, and when out in the Nile the market town of Nimule can be seen. Fish landed at Liri was either for home consumption, or sold at nearby markets particularly Nimule. Motorised transport boats run from Liri to Paanjala on the Moyo side of the river, which is the river border crossing point to South Sudan. By the end of fieldwork, the transport boats were intending to extend their network and also run from Liri straight to Nimule.

A number of homes have been built at the site, and men and women stay although they have permanent homes elsewhere. A small shop sells items such as sodas, cigarettes and soap. There is a latrine block. At this site, they used the common fishing methods with nets, but they also used baskets, *igwa*, placed in the river. This technique was brought to the area by fishermen from Masindi, two of whom stayed permanently. One man had been at Liri for eleven years and described how in Masindi, fishing is their life, a craft learnt from their ancestors⁵⁷.

⁵⁷ As he said to me, "We all know how to swim. If you drop a baby into the water and it sinks, you know it is not from your tribe, for our babies rise up again"

Onorio's place is also in Arinyapi sub-county, a few kilometres walk from Ogolo village. It is in fact the home of one family. As one fisherman explained to me, it was his grandfather that first settled here in 1980. He was from Paanjala (across the river in Moyo) and originally came here to cultivate. During Obote's regime there was a guerrilla group fighting the government. The army in West Nile were attacked in October 1980 and fled to Atiak, burning homes along the way. It was at this time in October 1980 that his grandfather decided to settle here. However, the national army followed them here and they took refuge in Nimule. They remained in Nimule until 1986 when they returned to settle again at this place.

Except in the dry months (January and February) when you can walk across the land, during much of the year it is in effect an island. There are a few houses for eighteen family heads although it is only the men who stay throughout the year. During the dry season, children and other family members stay, but in the rainy season they remain in Ogolo. It is a small clearing surrounded by banana and orange trees, and papyrus reeds. When it is hot inside, they sleep on the drying racks (for fish or cassava usually) in the centre of the homes under a mosquito net. Sometimes women come during the day to collect bananas and oranges. Cassava and maize are also grown. They take the maize to grinders in Nimule, which is about ten minutes by boat, to make flour for mingling in to posho (a staple food).

There is no '*wele*' (lagoon) here, only the '*were*' (current). They take nets in the evenings and then check them every morning. They also use the baskets, '*igwa*', which the men check daily. The men make the baskets and sell them on. A small sized basket costs 50-60,000 shillings, and a large is 100-130,000 shillings. They have three canoes which they share among themselves. They take the fish to Nimule to sell at the landing site there. At Onorio's place there is no revenue taken

from the Beach Management Unit (BMU) as they are 'at home'. The money the fishermen make is sent home to pay for children's school fees.

The river is their only water source, and there is no latrine so they dig a hole in the bush with a hoe. They use local herbs for certain sicknesses, for instance for cough they boil the leaves of the guava tree. Sometimes they go to Ogolo health centre II if they are sick, but they prefer Nimule hospital as it is nearer and "you get the service":

In Ogolo you may not get the drugs and they refer you to Dzaipi or Arinyapi, therefore it is better to go to Nimule. The service in Nimule is similar to Adjumani Hospital, and it is free, even for Ugandans. Moreover, the drugs are there. [Fisherman, 28.02.2014]

Otherwise, they had very few concerns, except, as was the case at the majority of the fishing sites, hippos disturbed them and when they come on land to feed (mainly in January to March) they destroyed the sugar cane and other crops.

The fishing sites along the river are therefore diverse, from the 'urbanising' lifestyle of Aliba Bitu, to the home at Onorio's Place. Some, like Asamvu and Onorio's Place, become cut off in the rainy seasons, and the majority become difficult to access due to the road conditions. Some have latrines, boreholes and other infrastructure, others do not. People at the landing sites have varying access to forms of healthcare. As is discussed in the following section, the dynamics of the local fish business also varies, although there are common features.

FISH BUSINESS

Fishing is governed centrally by the Fisheries Department of the Ministry of Agriculture, Animal Industry and Fisheries (MAAIF). Locally, it is controlled by the

District Fisheries Officer, who has representation at the sub-county level. Initially there was a Fisheries Officer for the sub-county, but this position has been amalgamated with the NAADs⁵⁸ co-ordinator (or vice versa) in many instances. The sub-counties are responsible for collecting revenue from registered fishing sites from the sale of licenses (for fishing and fishmongering) and the sale of 'Fish Movement Permits' to fishmongers selling at markets (the price varies depending on the quantity of fish and where the fish is being sold)⁵⁹. In order to obtain their license, fishers, fishmongers and food handlers were required to have a medical certificate. This included testing (and treatment if necessary) for HIV, tuberculosis, malaria and intestinal worms, although these tests were not always carried out in reality.

The day to day running of the landing sites is under the authority of a locally elected BMU which has a similar structure to the Local Councils (LC) at village level. A committee are elected by the landing site users. The committee is comprised of a Chairperson, Secretary, Treasurer and other positions decided locally. Women in particular must be represented on the committee, as well as the fishermen and fishmongers. The system is generally liked by people at the landing sites. It was often asserted that everyone is a member, and therefore they are collectively responsible for the running of the site.

Fishermen operated from traditional dugout canoes or small rowing boats. Few fishermen owned their own boat. Many rented for 30,000 Uganda shillings a month (i.e. 1000 shillings a day), with additional rent paid for nets and hooks. At

⁵⁸ The National Agricultural Advisory Services, a semi-autonomous public agency under MAAIF.

⁵⁹ For someone buying fish and taking to sell outside the district on motorcycle, the license is 250,000 /= per year. For someone with a boat, it is 10,000 /= for registration fee plus 25,000/= license for the boat (i.e. 35,000 /=) plus 10,000 /= registration fee and 25,000 /= license for the fisherman (i.e. 35,000 /=). So if you are one in the boat it is 70,000 /= per year; if you are two in the boat it is 105,000 /= per year. [BMU Chairman].

many sites, the owner was sometimes a 'rich' man not necessarily involved in the fish business directly. The main fishing practices include laying nets (*ambaruco*) and casting nets (*raca*) in the slow moving lagoons of the river (*wele*). At most sites, little fishing was carried out in the fast moving main river (*were*). Fishermen reported that the type of canoes they used and the types of fishing gears were not appropriate. In addition, some feared the main river. At certain sites at the southern borders of the districts, young boys regard learning to swim a necessary pre-requisite before learning to fish; fishermen at the majority of sites invariably did not learn to swim.

The predominant fish caught is tilapia (*foro*), mudfish (*ase*) and eel (*o'ji*)⁶⁰. Tilapia is sold in bunches of fish of similar size and the price varies across the sites. Five medium-sized tilapia may sell at a landing site for 5,000 Ugandan shillings⁶¹. Large tilapias are called 'LC5', after the LC5 Chairman at the district level. Nile perch is also caught but again because of the preferred fishing grounds and techniques used these are less common. However, if a large Nile perch is caught this can be very fruitful for the fisher who sells it at a price per kilo weight, sometimes reaching 50,000 to 100,000 Ugandan shillings per fish.

Fish is bought for home consumption or for selling at market. The majority of fishmongers are women who buy fresh fish from the fishermen at the boats when they land. They clean and gut the fish before either selling on fresh, or more often drying them over a smoking oven. After a few days when they have bought and dried enough they take the fish to markets either in the main towns in the district, or to Nimule in South Sudan using public transport means. Male fishmongers tend to buy the fish fresh and then sell on at markets that same day as fresh fish. These

⁶⁰ Local English terms used.

⁶¹ about £1.25

male fishmongers have their own motorbikes for transport and take the fish to the main markets in Adjumani or Moyo, or further afield to other towns in West Nile such as Arua, Yumbe and Koboko. Sometimes they employ women at the fish landing site to clean and gut the fish for them, paying 1000 Ugandan shillings to each for their labour.

For the fishmongers, a key element of the fish business is securing a sale, securing a catch. They deploy different strategies in order to do so. Some women bought fish from their husbands. If another fishmonger tried to buy from their husband, the woman would say: “*nyindre torozi ovi*” or “*nyindre sati ovi*”, meaning, ‘you look at their trousers (or shirt), implying, ‘are they your husband’s trousers (*torozi*), or shirt (*sati*)’?

Sometimes they made arrangements in advance with a fisherman, by providing cash up front such as the amount needed for the fishermen to rent their canoe and net for the day. This was a risky strategy, and required trust between the fisherman and woman. Some women would not go into such a deal as they deemed the risk too great. They suspected the fisherman may sell the fish in the water to fishmongers (often male) who take boats out into the river. These fishmongers were called ‘*lejigo*’, a term derived from ‘LGO’, Local Government Officers, who were the ones who originally used motorboats in the river for enforcing regulations. The women also feared that fishermen would land the fish at another site and return to their original landing site with no or little catch, declaring ‘*ebi iyo*’, ‘there is no fish’. Making arrangements in advance was one way for the fishmongers to secure a fish catch, but it was not a guarantee.

At many of the fishing sites in Obongi County, it was the female fishmongers who owned (or at least rented) the boats and nets. They then rented them to the fishermen, with the agreement that they would get first priority to buy the fish. If

a fisherman continually brought back a low catch, the women could rent the boat to another. At these sites, the female fishmongers in particular drove hard bargains, often setting the price of individual fish sales.

For instance, one woman who worked in a hotel bought mudfish daily. A young fisherman selling one initially wanted 12,000 shillings but came to 10,000. After some time, the woman paid 8,000 shillings. It was similar with other sales. In this case, the female fishmonger was well-established in the business and had more bargaining power than the young fisherman. However, when it was a large fish catch landed (perhaps 200,000 shillings worth of fish in a boat of five fishermen), it was the fishermen who set the price.

Women bought the boats and fishing gears through saving, often through micro-credit groups. One woman Bianca⁶², who had been in the fish business for eighteen years, explained her story to me. Bianca is supporting her four children and the household as her husband is away for work far from the home town. At first she rented a canoe and let it out to the fishermen. However, she reported, 'you lose some of the profit from the fish in paying the rent'. For seven years she saved on her own accord. At first she didn't plan to buy a boat. She used her money to buy goats, and when they bred sold them on. She also bought a cow, which had produced, meaning she owned two cows herself. Her husband owned other cows. (Often, other cattle that belonged to the husband's clan or family were tied up in paying bride price. Goats were sold to cover expenses such as hospital bills for operations, but if needed sometimes cattle would also be sold to pay a witchdoctor for instance.)

⁶² pseudonym

Having bought and sold livestock, Bianca started saving for a boat. When she had 480,000 shillings she bought her first boat (eleven years ago). She continued saving, and when she had 450,000 shillings she bought a second boat (three years ago). She rented out the boats, collecting revenue, and in addition is guaranteed the fish sale. She tended to keep all the fish for her fishmongering, but sometimes sold to other women who are buying for home consumption at 1000 or 2000 Uganda shillings.

She explained how the fish business worked at the landing site she used, and with this the prominence of women. There are over 100 boats at this landing site, and less than five boats were owned by men. At the time, the boats were in demand and rented for 2000 shillings per day (60,000 per month), compared to the usual price of 1000 shillings per day⁶³. One way that the women at this site achieved this was by saving through micro-finance and credit groups. As Bianca explained, all the women at the landing site are in credit groups. They have formed two credit groups at the landing site itself, Awizi A and B⁶⁴ (there is one fisherman in these groups, the rest are women). They call themselves Awizi (widows); they are not widows, *“but our men do not support us, they just spend their time in town chewing marungi, and so the women call themselves widows.”* This sentiment was also reflected at the International Women’s Day Celebrations in a speech by the Obongi LC III, (of note, it was said on a day that celebrated women in Obongi):

... “it is the women at the landing sites who own boats; they are managing the fish business, the home.” He calls “for the men to step up and

⁶³ 1000 shillings per day was the price quoted across the other sites in Moyo and Adjumani Districts.

⁶⁴ They meet once a week. There are two savings in each group: a credit savings where each puts in what they can each week and interest is carried on the loan; the second is called the 'social fund' where each person puts in 1000 shillings per week, and the loan does not carry any interest.

participate⁶⁵, to join with the women to improve the income and support the family and household.”

The women used their money to pay for children’s school fees and other household needs. Bianca continued: *“The women here have plans, and business and saving plans at that.”*

Not surprisingly, tension arose as women in the fish business were becoming financially independent. One man suggested women were now ‘big headed’ and didn’t share their earnings with their husband. Two women, overhearing replied to me in English:

‘it is not like that, but our men do not provide anything, it is us taking care of school fees, soap, salt, sugar etc. It depends on your relationship, some people will trust their husband if you have a good relationship. But most of our men are not good like that, so the women are taking care of themselves. Men don't support their wives here, they are selfish.’

Many men would contradict this, and indeed in other cases men and women who were married worked in the fish business together in order that all the profits were pooled for the household. For fishermen, the money is cash in hand but not always reliable. Each day they can go to the river with nothing, some days they come back with nothing, on other days they receive something. If the fish catch is low in one area, they move to another site. For women, it is not so easy for them to move to other sites. While it could be hard to get established in the fish business and to secure a fish arrangement with a fisherman, they adopted many different strategies to do so. Once established, while the profit from preparing and selling on the fish

⁶⁵ The theme was: ‘men and boys in partnership with women and girls’.

was relatively little and not realised immediately, they were able to sustain their business, and for the women in Obongi, to expand it to owning boats and livestock.

Men and women in the fish business were working hard to make a living along the river. This not only caused tensions between themselves, but tensions with local authorities. While disputes often arose, in most cases these were managed between the individuals:

A quarrel breaks out between a fisherman and a woman. He has just come in with his two paddles and bag. They fight over the paddles. The woman takes one and the man marches off to the centre. When the woman comes past about one hour later, having finished cleaning her fish, she explains that that fisherman owes her a balance of 1000 shillings which he has not yet given and is still refusing. So she is going to sell his paddle now for 1000 shillings to anybody who will buy. [A paddle is normally about 5000 shillings.]

Quarrels like this often occurred when pre-arrangements had been made and were not fulfilled, or when fishermen went to the river with somebody else's equipment for instance. At times, fishermen were accused of taking fish from other people's nets. These were day to day problems with the fish business, but for the majority of the time and at the majority of sites, it was conflict free.

When conflicts did arise the next port of call for managing them was the BMU. During an early stage of fieldwork, a dispute occurred between two fishing sites across the river from each other. When we visited one landing site, people there were angry because a number of their fishermen had been arrested in the river by the BMU at another landing site. Allegedly, one man threatened to cut off the ear of another. It turns out that the fishermen arrested had been using illegal fishing

nets. They had been taken to the sub-county offices, their nets were destroyed, and the men were released the following morning. The issue was quickly resolved and business resumed as normal.

Disputes like this were normally settled through the BMU and referred to the LC if necessary. Often a meeting was held with members of the BMU, LC or elders and others at the landing site. The dispute was discussed and while in the past an animal (often a chicken) would be sacrificed and shared; now they were settled by a fine agreed by those present. However, in other instances it was difficult for those elected as BMU or LC to enforce regulations. They are in a position between the fishing authorities at district and sub-county level, and their fellow fishermen and women that they live and work alongside. At one site, this was particularly a problem:

We were at a landing site that used to be very busy. One day we sat with the women while a few boats entered the landing site one by one over the morning. No market due had been paid and, so the women were explaining, the place was dirty. *“The fisheries want us to shift to [another landing site] because the fishermen are not using the right gear.”*

As we were sat there, it was clear that the fish business was still continuing. We later met the LC1. He explained,

“the problem with the fisheries is that the men here are using gears that are not wanted – this one that you drag along (korokota). So, the fisheries told the people to stop buying at [this landing site] and they were asked to shift to [another landing site], where it is regulated.”

A man asks, “but why not just tell these men here to stop using korokota?”

The LC replies, “because if you just tell them politely, they will not do it. So the fisheries are trying to force them. But the sub-county are not the ones trying to force them”. (i.e. the BMU and LC enforce the regulations stipulated by Fisheries at the sub-county or district level) [Fieldnotes extract, 06.03.2014]

While fishing activities reduced at this site they did not stop completely. The BMU could not enforce the restrictions. With the landing site officially closed, he also could not collect fees from the fishers and fishmongers and nobody could be requested to keep the area clean. The BMU Chairman described his position, and the difficult situation he was in, being both a member of the community and an authority at the landing site:

It used to be that the fisheries collected revenue from the landing site but since January this year they have refused to give licenses for those here because of the use of koro kota (a trawling method) and other illegal nets and fishing practices (e.g. tycoon – where fishermen use a big wooden stick to beat the surface water and disturb the fish, including the breeding places) ...

It is difficult for the BMU to enforce fish net rules because those using will say, 'I will burn your house, I will buy ten litres of fuel and burn your house', so we cannot act. But the fisheries try to enforce it. Maybe they will send security down here, or arrest those using the nets. But for now, they have just stopped issuing licenses. Some fishers have moved – shifted to other sites. But others remain here. [Discussion with BMU, 10.03.2014]

The men and women at this site resisted the attempts by the authorities to regulate their fishing practices. In fact, while some fishermen moved to other sites many

had gone to sites in a neighbouring district where the regulations were also not enforced. Some women had moved into other small businesses such as selling food crops at the local market, but others continued buying fish from those fishermen who also remained. The women resisted because they could not move to another site further away as they were also required to manage their home and children. In addition, they would have to re-establish networks of who to buy from at other fishing sites.

Relationships with the authorities were not always as fraught as this though, and often it was a site for negotiating between the fishers, BMU and fishing authorities. One BMU chairman explained why he did not collect revenue from the fishermen and fishmongers:

My grandfather came here in 1954 and started this area for fetching water for the family. In 1962 there was a lot of flooding and it opened up the landing site. It started being used as a fish landing site in 1993. Then five years ago the sub-county said that there should be a way to get revenue from the landing site. However as BMU chairman I am reluctant to collect the money. There are no facilities at the landing site therefore it is not fair to collect revenue. In the last year, I only collected for two months. The revenue to the sub-county is not regular. It is meant to be 25,000 (shillings) per month. Until the sub-county have delivered infrastructure, I am reluctant to send in the revenue. The fishermen say to me, 'why should we pay when there are no facilities'. [In English; 30.07.2013]

This was the case for a number of sites. They had started as small-scale village landing sites. As fishing expanded, the number of users grew. But equally, the number could decrease depending on the season, or long-term changes in the fish

catch. There were no repercussions for this landing site when revenue was not paid to the sub-county. Indeed, for many sites, they were village landing sites where little revenue could be expected anyway. Some had developed into busy and more prosperous sites and these were the ones that the authorities focused on, both in developing infrastructure and enforcing regulations.

In this context, there were times when people also resisted public health authorities. In one instance, women allegedly made threats of local poisoning when the environmental and public health officers tried to improve the food hygiene standards of those selling food to the public (one having become ill following eating there). During this research, while carrying out water contact observation at one landing site it became clear that people were suspicious about it. We were seen as another authority, sitting and taking notes. This was not a surprising reaction. This landing site had been in contention with the fishing authorities for the use of illegal nets, although the fish business was still booming. In addition, on that day the sub-county had carried out environmental health checks at each home. It is a regulation that all households must have a latrine as well as other sanitation measures such as hand-washing facilities. Spot checks were carried out by the sub-county along with the police, and if a household was found without they were fined. When these checks were carried out in some places, it culminated in a number of individuals being arrested.

These meetings with public health authorities did not always end up with confrontation though. We had hoped to carry out the survey at a busy fishing island, however a few weeks before the island flooded and people staying there had dispersed. As the island began to flood, there had been discussion by the sub-county and environmental health officer on whether they needed to enforce the Public Health Act and order people to leave the island. They were concerned of the

potential for outbreaks of water-borne diseases like cholera, because there were no latrines and the only water source was the river. It appeared these concerns were broader than the immediate concerns regarding the flooding, but the flooding exemplified the matter further. However, in the end the fishers reported that when the water level rose so high they could not stay there anyway, and so they made their own decision to leave.

CONCLUSION: 'HEALTH IS OUR HUMAN RIGHT'

While there has been a long history of insecurity and upheaval in this region, people are trying to make a living in relative peace. Along the river, the main security concerns now were from attacks by wild animals, hippos⁶⁶, and the threat of drowning. This chapter has demonstrated the marginal existence of many fisherfolk, those living and working along the River Nile. In part this is a physical or geographical positioning. Yet there has also been historical political marginalisation. This region has experienced devastation from ivory and slave traders, social changes brought about during different colonial rules and decades of insecurity. Development and modernity (Allen and Storm, 2012) were at the forefront of some people's minds. Indeed, there have been significant changes especially in the last few years, with signs of development to come (for example the extension of the electricity power lines).

There was reflection on another side to development though. I was having a conversation with a Madi man in his thirties. He was born in Moyo District along the river and spent his early years in exile in southern Sudan before returning to his father's homeland as a young boy. We were sat outside in a trading centre on the main road between Gulu, Adjumani, Moyo and parts of South Sudan. There were a

⁶⁶ On our first visit to Liri, a man had been attacked by a hippo and died on his way to Moyo hospital.

number of shops and small bars, and a busy market once a week. There was no electricity in the trading centre, although pylons were being built to connect them at some point in the future. It was pitch black, apart from the light of the moon. The sound of generators from phone charging shops provided a constant background noise. He asked what it was like living in London:

'I hear in London that some people live in cardboard boxes. The same happens in Kampala.' He pauses. *'That's a sign of development.'*

We laughed at the irony. Kampala and its 'development' were far removed from the trading centre we were sat in along the Nile in the border area of Moyo and Adjumani districts. The majority of people struggled economically, eking out a living through fishing, farming and small businesses. You could often see people with mental illness wandering the streets, dishevelled. Yet, without being idealistic, whatever the situation it was often said that people had a home, somewhere to go, and somewhere where food was prepared. The idea of living in cardboard boxes was absurd.

The day to day reality is that those involved in fishing are finding ways to make a living, some relatively successfully, but it was always an everyday necessity. People involved in fishing were resisting the neglect and marginalisation, in small or larger ways. As we have seen, those living and working along the river exert agency between themselves and local authorities through everyday forms of resistance (Scott, 1987), but it also goes beyond these local dynamics of power. People were not just passive victims of power, neglect and marginalisation.

People were demanding infrastructure, be it facilities at the landing sites, roads or health services. The Obongi ambulance discussed in the introduction was a political statement, a symbol of opposition. It was also a symbol of inclusion and challenged

neglect and marginalisation. The initial request for the ambulance had come from a woman's group. The MP, who had trained and worked as a clinical officer before going into politics, had been instrumental in lobbying for the ambulance along with the Obongi Development Initiative. In other areas, particularly in Obongi but also elsewhere, there were similar visions although they were not so readily realised. On a first visit to one remote site, walking from the canoe to the village we passed a home. A young man jumped out and in English said: "*It is good you are here. We have a right. Health is our human right!*" His use of a human rights discourse was striking, and was reflected in other instances when people talked about biomedical healthcare. Frustrations towards the limited provision of biomedical healthcare locally also fostered mistrust towards it in some cases, as will be discussed in later chapters.

A number of factors have shaped people's perceptions of biomedical health services and healing more generally. They are arguably based around trust and knowledge, as will be demonstrated in discussions on schistosomiasis, Buruli ulcer and hepatitis B. The following chapter is on a neglected tropical disease, schistosomiasis, and the public health intervention that has been implemented to control it – mass drug administration. Despite sites of resistance between fisherfolk and authority including public health, there has been an overwhelming positive response to mass drug administration. This is one aspect of why mass drug administration has been successful in reducing levels of infection in the area. But the following chapter also takes the analysis further, in investigating the local context of schistosomiasis control.

4. MASS DRUG ADMINISTRATION: IS IT SUCCESSFULLY CONTROLLING INTESTINAL SCHISTOSOMIASIS?

“We are the rubbish pit for worms!” was a phrase commonly said by fishermen during fieldwork in 2009. Schistosomiasis, or *bilharzia* as it is known locally, was one of these worms (*obu*). It was a disease affecting people along the river. To control transmission and reduce the morbidity associated with intestinal schistosomiasis infection (*S. mansoni*), mass drug administration of praziquantel has been introduced since the early 2000’s in many endemic areas, including Moyo and Adjumani districts. In 2009, with a Vector Control Officer we carried out a small parasitological survey among adults staying on one fishing island in the River Nile in Moyo district. The results suggested that infection levels were low. These results were surprising given the literature on schistosomiasis control among fishers around Lakes Albert and Victoria where high rates of re-infection have been found despite praziquantel distributions (Kabatereine et al 2001; Seto et al 2012; Parker et al 2012). While the results were from a small sample of people, it raised questions. Is this low prevalence of schistosomiasis more widespread along the river? Is it being sustained?

We therefore carried out a broader parasitological survey in 2013, which also found low levels of infection among people at twelve fish landing sites along the river. At the sites surveyed we identified only three cases of *S. mansoni* among 383 adults tested. Given that there have been difficulties reported in controlling schistosomiasis and problems with mass drug administration elsewhere, is mass drug administration successfully controlling schistosomiasis in Moyo and Adjumani? If so, why has it been successful here and not elsewhere? In order to answer these

questions, we used multiple methods of enquiry trying to build a picture of the many factors that might help explain this parasitological data.

In this chapter⁶⁷ I argue that while the free distribution of praziquantel is likely to have had an impact, it is unlikely that the low prevalence of infection can be attributed to mass drug administration alone. Changing fishing livelihoods, access to water and sanitation facilities, hygiene practices and use of certain anti-malarial treatments all influence levels of infection. Therefore, the role of mass drug administration needs to be understood within this context. Drawing upon both long-term ethnographic fieldwork and the parasitological research, this chapter seeks to explain low levels of schistosomiasis infection seen among fisherfolk, through a discussion of the biosocial complexities of intestinal schistosomiasis. It therefore explores the social and structural drivers that enable and mitigate biological risk in this context, going beyond mass drug administration. It highlights the success and challenges for schistosomiasis control. By examining a successful case, it analyses why the one size fits all policy of mass drug administration has worked in this context. The answer, although still unclear, is likely due to the context in which the distribution of drugs has occurred.

The first section provides an overview of schistosomiasis. The following section presents the parasitological findings from the cross-sectional survey and draws on available data on the prevalence of *S. mansoni* in the area to demonstrate that rates of schistosomiasis appear to have reduced among this population. These findings are then discussed in relation to mass drug administration. It is shown that while this is likely to have had an impact on disease rates, it is unlikely that the low prevalence is due to mass drug administration alone, but must be understood

⁶⁷ This chapter is based on a paper in preparation, "Low prevalence of intestinal schistosomiasis among fisherfolk living along the River Nile in northwestern Uganda: a biosocial investigation."

within the context of other biological and social factors that influence vulnerability to schistosomiasis and affect control. There are other biomedical factors that may have contributed to the decreased levels of infection. In particular, there is a high use of anti-malarials that have additional anti-schistosome effects. Other aspects may have enabled sustained control more generally, such as movement patterns in this border area. In addition, water, sanitation and hygiene at the landing sites influence the peculiarities of transmission at the landing sites.

This chapter therefore demonstrates the value of taking an ethnographic-epidemiological approach methodologically and analytically, in order to understand the biosocial complexities that lie behind the parasitological results. It argues that schistosomiasis control in this area, and the seeming success of mass drug administration, has occurred within the context of a number of biological and social factors and therefore depends on this biosocial context. Whilst the findings are encouraging, to sustain control over time will require a reconsideration of the social and structural drivers that enable and mitigate biological risk.

INTESTINAL SCHISTOSOMIASIS AND SOIL-TRANSMITTED HELMINTHS

Schistosomiasis is one of the neglected tropical diseases. Like many of these diseases of poverty it predominantly affects rural populations. The World Health Organisation (WHO) (2012) estimates that over 200 million people worldwide are infected with schistosomiasis with over 600 million people at risk. Eighty-five percent of those infected are living in the African continent (Chitsulo et al, 2000, p.42). There are five main species of schistosome that cause disease in humans (*S. mansoni*, *S. haematobium*, *S. japonicum*, *S. mekongi* and *S. intercalatum*) (WHO 1987). *S. mansoni* which causes intestinal disease and *S. haematobium* which causes urinary disease are the most common. Their distribution differs and in some

areas both species are found. *S. mansoni* is found in Africa (both North Africa and sub-Saharan Africa), South America, and some areas of the Middle East. This research is on intestinal schistosomiasis caused by *S. mansoni*, the species that is endemic in Moyo and Adjumani districts.

S. mansoni can have varying effects in people, from acute intestinal symptoms (blood in the stools), to chronic complications affecting the liver and spleen (distended abdomen from portal hypertension). The disease is caused by eggs released from adult worms living inside the blood vessels for the intestinal tract and liver. Transmission occurs when faeces containing the parasite eggs contaminate rivers and lakes. The parasite eggs hatch many miracidia (tiny parasites) that enter and develop inside suitable freshwater snail hosts. They then release multiple microscopic cercariae into the water which, when a person comes in contact with the water, enter the body through the skin (see Gryseels et al 2006).

There is often overlap with schistosomiasis and other intestinal worms, the soil-transmitted helminths (*Ascaris lumbricoides* also known as roundworm, *Trichuris trichiura* or whipworm, and *Necator americanus* and *Ancylostoma duodenale* both of which are hookworms). The life cycles differ to schistosomiasis. Again, eggs are released from an infected person's faeces that contaminate the environment. They are either transmitted through ingestion of the parasite eggs, or in the case of hookworm the eggs hatch in the soil and penetrate humans' skin. They do not involve the intermediary stage of the freshwater snail hosts and therefore do not necessarily occur along the shores of rivers and lakes. However, they do occur in areas where sanitation and safe water sources are limited or lacking. Therefore, while their distribution is more widespread than schistosomiasis, there is also an overlap between the intestinal helminths (both soil-transmitted and schistosomiasis). The public health programme to control intestinal worms is often

delivered simultaneously for schistosomiasis and soil-transmitted helminths. In this research, while the main disease investigated among the fisherfolk was schistosomiasis, we also tested for other soil-transmitted helminths in the parasitological survey. However, this chapter will mainly deal with schistosomiasis, referencing the findings in relation to soil-transmitted helminths where necessary.

Returning to intestinal schistosomiasis, there are notable micro-geographical variations in patterns of disease (Gryseels, 1991). In one region, infection rates can vary between neighbouring villages. Even within one village, infection patterns vary between individuals. These micro-geographical variations can be explained by complex interactions between biological, social, behavioural and environmental factors determining transmission and vulnerability to schistosomiasis (Grimes et al 2015).

Following WHO recommendations to treat 75% of school children in high endemic areas (WHO, 2002), annual mass drug administration with praziquantel was introduced in countries such as Uganda from 2003, to reduce morbidity from schistosomiasis (Kazibwe et al 2003). The focus of the programme is predominantly on primary school children as infection peaks within this age group (Kabatereine et al 2004). In addition, communities at high occupational risk, such as fisherfolk, are targeted through mass drug administration. This aims to interrupt or reduce transmission through population based treatment, which is offered irrespective of whether an individual is infected or not.

In many areas, this is distributed as part of an integrated programme on neglected tropical diseases. Not only do these diseases overlap, but for some, the treatment overlaps too. Therefore, mass drug administration involves the co-administration of drugs for certain neglected tropical diseases. For instance, in Moyo and Adjumani districts praziquantel is distributed alone for schistosomiasis. At another

time (theoretically at least two weeks apart from the praziquantel distribution), albendazole and ivermectin are distributed for hookworms (which are treated by albendazole alone), lymphatic filariasis (albendazole and ivermectin jointly), and onchocerciasis (ivermectin alone).

There have been challenges for mass drug administration. Local level research has found low drug coverage along Lake Victoria and Lake Albert in Uganda (Parker et al 2008; Parker et al 2012; Muhumuza et al 2013; Muhumuza et al 2014).

Furthermore, despite the distribution of praziquantel, high rates of infection around Lake Victoria and Lake Albert continue to be reported (Kabeteine et al 2011; Seto et al 2012).

Yet, among adult fisherfolk in Madi areas of northwestern Uganda along the River Nile, it appeared that transmission had reduced. During fieldwork in 2009, in the small study carried out with District Vector Control on one fishing island, only one case of *S. mansoni* was found out of 31 fisherfolk tested (Parker et al 2012). This research was based on limited parasitological data, but it was still surprising given that those fisherfolk tested spent the majority of their time at various fishing sites along the river. On the island there were no sanitation facilities or safe water provision. It was a compact island, and it was a busy fishing ground with people having daily water contact. Knowing that schistosomiasis, known locally by its common name *bilharzia* or more generally as *obu* ('worms'), was common (along with many other diseases) among those along the river many would report, '*we are the rubbish pit for worms!*' Yet the parasitological results suggested that this was less the case than one might expect.

PARASITOLOGICAL FINDINGS

Similar parasitological findings⁶⁸ were again found in 2013. The overall prevalence of *S. mansoni* among the fisherfolk tested in both districts was 0.8%. Three adults were found with *S. mansoni* at three sites: two women at Adjumani sites (aged 34 and 35 years old) and one man at a Moyo site (aged 22 years old). One woman had a high intensity infection (479 mean eggs per gram); the other two adults had low intensity infection (24 mean eggs per gram; 60 mean eggs per gram). At the individual sites, prevalence among those tested was 2%, 3.5% and 3.5%. At the other nine sites, prevalence was 0% among those tested. Hookworm was prevalent in certain areas and identified at three sites. At two of these sites, one person (4%) was diagnosed with hookworm at each, and at the other site, four people (11%) were diagnosed. Other soil-transmitted helminths were not identified in the parasitological survey.

These findings of low levels of schistosomiasis infection were also seen at local health centres that had established laboratories. There were only two health centres near the river in Moyo district that had microscopy facilities. Therefore, there is limited data on schistosomiasis diagnoses made outside a survey setting. At one of these health centres, four cases had been detected in 2013 out of approximately 500 people (men, women and children) who had their stool examined. At the other health centre, available laboratory registers from 2010 onwards showed no *S. mansoni* had been detected on stool examination. In Adjumani district, at the time of the fieldwork, there were no health centres relatively near the fish landing sites that had microscopy facilities.

It does appear that transmission of *S. mansoni* among fisherfolk at the sites studied is low. Yet data on *S. mansoni* demonstrates that it had been higher in this area. Nelson (1958, in Bradley 1975 p.51) conducted *S. mansoni* surveys in West Nile

⁶⁸ Only relevant material from the survey data is presented in this chapter.

District between 1951 and 1954 and estimated an average infection rate in West and East Madi (now Moyo and Adjumani Districts respectively) of more than 50%. Bradley also reported that the prevalence of *S. mansoni* “is high along the river except for a small area north of Rhino Camp where endemic cases seem to be absent” (p.52) (Rhino Camp being just south of Obongi County next to Aliba Bitu). The prevalence varied from 2% in the Rigbo-Obongi area, to 29.5% in the Laropi-Dufile area in Moyo District (Nelson, reported in WHO 1987).

Vector Control Division of the Ugandan Ministry of Health⁶⁹ have carried out a number of surveys on school children for both initial mapping exercises and ongoing monitoring of mass drug administration. The initial mapping exercises determined areas for population-based treatment based on parasitological testing in schools (Brooker et al 2005). Six primary schools in Moyo District were surveyed in 2003, 2004, 2005 and 2007, and twelve in 2006. The overall prevalence was 20.1% in 2003 with cases found at every site surveyed (ranging between 7.6% and 35% at the sites). In 2007, the overall prevalence was 9.6% with the number of cases identified remaining high at some sites, but absent at others (ranging between 0 and 32.7%). The most recent survey carried out in the two districts was in 2011. In Adjumani, the overall prevalence was 9.6% in the nine primary schools surveyed, and ranged from 0 to 26%. In Moyo, in the nine primary schools surveyed, the overall prevalence was 2.5% and ranged from 0% to 8%, demonstrating a further reduction from the 2003 to 2007 surveys. There have been very few studies in Adjumani district, but this data from Moyo primary schools suggests that over the course of mass drug administration, the overall prevalence of schistosomiasis has decreased and while it was initially being found at all sites surveyed, some sites in later surveys didn't identify cases.

⁶⁹ The data presented in the following two paragraphs was kindly provided by Vector Control Division, Kampala.

Disease mapping was carried out in primary schools to determine the need for population-based treatment, therefore pre mass drug administration surveys were not carried out on adults. However, a few surveys have been conducted by Vector Control Division. In 2008, two sub-counties in Moyo District along the River Nile were surveyed. Out of five communities in one sub-county, the overall prevalence was 3.6% (ranging from 0 to 12.5% at the different sites). Out of four communities in the other sub-county, the overall prevalence was 29.2% (ranging from 0 to 66.7%). In 2011, two communities were surveyed in Moyo by Vector Control and the prevalence of *S. mansoni* was 8% and 6%.

It is important to note that in Adjumani District there were foci of disease in inland areas away from the River Nile (findings from health centre laboratory records and discussions with District Vector Control). Importantly, these areas had not received mass drug administration. At one health centre, six cases were detected in July and August 2013. This is likely to be significant for the control of schistosomiasis in the district, as will be discussed later in the chapter. In addition, at Adjumani hospital people who didn't live or work along the River Nile were occasionally admitted with signs of chronic schistosomiasis. The following fieldnotes from a hospital visit illustrate this:

There is one female patient on the ward who has hepatosplenomegaly. She brings in her medical report with ultrasound scan report. It shows portal hypertension secondary to portal vein fibrosis. She reports that many in her village have similar swollen abdomens. They are near a river; they collect water from the rivers and streams, although she is not living in a sub-county that borders the Nile itself (and therefore doesn't receive mass drug administration). She has had the hepatosplenomegaly/distended abdomen

since 2006. She reports that she didn't go into exile to Sudan, she remained within Uganda. The Sudanese refugees later came to their area.

Her most recent stool is negative for S. mansoni, but [the clinician] prescribes praziquantel as the ultrasound scan findings and history are consistent with chronic schistosomiasis changes."

While in Adjumani it appears that schistosomiasis is in fact still a problem in areas away from the River Nile, the data presented here suggests that prevalence of *S. mansoni* has reduced at sites along the river. When feeding back the results to people at the fishing sites, some fisherfolk doubted the findings as they still suffered from intestinal symptoms and had daily contact with the river water. The objective rates of schistosomiasis disease as diagnosed on microscopy did not reflect people's experiences of suffering from intestinal illness.

Yet many corroborated the findings, recalling that schistosomiasis had been a significant health problem in the area before mass drug administration was introduced. As one fisherman reported in a group discussion:

"During those days [referring to 1980's/1990's], bilharzia [schistosomiasis] was there. One man was diagnosed in 2003 here. Before exile, it was so much... The symptoms at that time were stomach ache, dysentery and diarrhoea, and there were some people with swollen stomachs; this was so common. When people arrived from Sudan [in the late 1980's] it was common. When the distribution started, it started reducing".

It is difficult to say with certainty due to limited data among adults, but comparing levels of infection found at the beginning of mass drug administration in 2003 to ten years later in 2013, it does appear that levels of infection have reduced. Is this finding due to mass drug administration?

MASS DRUG ADMINISTRATION

Is mass drug administration successfully controlling intestinal schistosomiasis in this population?

Mass drug administration has been the sole specific public health intervention for controlling schistosomiasis in this area, however distribution and actual consumption of praziquantel each year is inconsistent. In Moyo District, praziquantel for schistosomiasis was distributed district-wide, first and foremost to primary schools, and then to communities if there was adequate praziquantel stock. In Adjumani, it was only distributed to primary schools and villages located within two kilometres of the River Nile. Across both districts, mass drug administration for adults was distributed within villages. Therefore, if the fishing sites are not within a village, the fisherfolk had to return elsewhere to access the distribution. In both districts, community-wide distributions did not necessarily happen every year. In fact, between April and August 2013, praziquantel was distributed in Moyo District; however, in Adjumani District, only ivermectin and albendazole were distributed for onchocerciasis and lymphatic filariasis. There are therefore, not unexpectedly, differences in the uptake of the distribution across the districts.

Answers from the survey questionnaire suggested that uptake of praziquantel was predominantly lower than 75%. The total percentage of participants who reported to have taken praziquantel in 2013 was 55.9%. This was 66.2% in Moyo, varying between 41.4% and 79.4% across the sites. Despite the fact that there was not a distribution in 2013, 43.4% of participants in Adjumani District reported to have taken praziquantel in 2013 (varying between 34.4% and 57.6% across the sites). Praziquantel tablets (large, with a distinctive pungent smell, of which adults typically take three or four tablets) are distinct from ivermectin (small tablets) and albendazole (which is large but only one is given); there was therefore little

confusion between the distributions. In some areas people reported taking tablets left over from previous years, and a few individuals in Adjumani District reported to have sought praziquantel from the distribution in Moyo District. Either way, when there was a distribution not everybody accessed it or actually consumed the tablets. When there wasn't a distribution, some people found ways to access the tablets.

The vast majority of people obtained praziquantel through the mass drug administration. 94.8% of participants in Moyo, and 91.3% in Adjumani, reported having received praziquantel in this way at least once. This is compared to 23.3% in Moyo and 16.8% in Adjumani who reported to have taken praziquantel from private clinics or health centres at least once.

A minority of people reported to have never taken praziquantel: 3.8% in Moyo and 3.5% in Adjumani. This was a concern for district staff. Commenting on this, one asked:

'Why are certain people not interested in the free drug? Why are they not ready to take it? Why do they not seek the drug when it is free and available from the VHT⁷⁰?'

These comments were made when discussing the distribution in Obongi County in particular, but our survey results show that differing levels of uptake occurred across all the sites we visited⁷¹, for varying reasons. There were some people who remained reluctant to take praziquantel from the free distribution. In group discussions and conversations, some fisherfolk questioned the logic of the distribution when they did not feel unwell and had not been tested for the disease, as one fisherman asked:

⁷⁰ Village Health Team

⁷¹ See appendix 4.

'Why should I take the drug, if I am without disease?'

Others stated that their parents and grandparents had lived healthily to an old age using the river water as they currently do. It was also reported that some did not take praziquantel because they had consumed alcohol which is contraindicated.

Additionally, there were logistical constraints due to the nature of the mobile lifestyle of fisherfolk. Those who missed the distribution were often away at the time cultivating, fishing, taking produce to market or visiting relatives elsewhere. A group of fishermen described their problems in accessing the distribution:

Everybody knows about the taking of drugs, but if you are not found, for example because you are in the Nile, they say you go to (the VHTs) home. But you go maybe three times and they are not there so you miss. The drugs should be left at your place so that they can take them later. They don't distribute at [one fishing site with a number of tukuls], they say to go to [the VHT's] home."

At some sites, people raised concerns that the VHTs did not distribute to everyone but chose who to offer treatment to. This made some people reluctant to seek out the treatment. In other studies, concerns regarding side effects (particularly when praziquantel is taken without food) have explained the reluctance to consume praziquantel (e.g. Parker et al 2012, Muhumuza et al 2014). Concerns about side effects were reported in previous research in Moyo and Adjumani Districts yet it was noted that this did not necessarily deter people from taking the drugs (Parker et al 2012). Indeed, even if side effects were experienced, for some people, this justified the need to take them, as reported in a group discussion:

'If you have [side effects] it means you had the worms'.

From many of our discussions on bilharzia and mass drug administration, a general perception was that these medicines had reduced the rate of disease among the population, and that they needed these drugs because they remained at risk along the river. Even though the exact transmission mechanism for *bilharzia* was not always known (with some questioning if it was from standing in the river or drinking the river water), it was known to be transmitted by or along the river. The majority of people therefore took praziquantel from the mass drug administration if it was delivered at a time when they were available. Others even sought it out if they could. While a few people were reluctant to take the drugs if they were not unwell, the vast majority of people were keen for the distribution to continue.

This is in keeping with previous research in this area. The response to mass drug administration as a vertical health programme in other areas of Uganda and Tanzania (Parker, Allen and Hastings, 2008; Parker and Allen, 2013) has been problematic, however, among the Madi of northwestern Uganda it has been noted that there has been a more generalized acceptance of the programme (Parker et al 2012; Allen and Storm 2012). This acceptance, it is suggested, is related to the historical, political and social context of this area. In particular, the legacy of colonial sleeping sickness control, more recent experiences benefitting from refugee humanitarian relief programmes and the influence and support of the Catholic Church have all been influential (Parker et al 2012; Allen & Storm 2012). In addition, local healing practices and the use of local herbs for treatment and symptomatic relief, are an important part of healthcare choices in this area (discussed more in the following chapters), but they are often used alongside biomedical healthcare and don't necessarily conflict with using biomedical health programmes (Allen and Storm 2012). For bilharzia, one fisherman explained, '*erua Madi a di dri uci uci*' (meaning loosely translated as: erua Madi is just used for 'what

to do?') [18.02.14]. While others reported that there were herbs that treated *obu* (worms) like bilharzia, and in the past this had been the management, this was not reported to be instead of mass drug administration now.

While there is high demand for mass drug administration in this area, the findings demonstrate that actual uptake is inconsistent. Therefore, are low infection levels attributable to mass drug administration alone?

It is likely that the distribution has had an impact. Significantly, there are additional benefits of praziquantel treatment that enhance the effectiveness of mass drug administration among adults. In addition to the immediate effects of praziquantel treating current infection, there are longer-term immunological effects providing some protection against future infection in adults (Dunne et al 2006). Age-related patterns of infection and responsiveness to praziquantel treatment may therefore have a role in explaining low levels of infection in this population (Kabatereine et al 2004). However, higher levels of infection post treatment have been seen among Lake Albert fishermen and women (Seto et al 2012) and along Lake Victoria (Kabatereine et al 2011) despite mass drug administration. This suggests that the distribution alone is not sufficient in controlling schistosomiasis. Why is it different among fisherfolk in Moyo and Adjumani? Further explanations must be sought as to what else has enabled low levels of infection, explanations found within the biosocial context of schistosomiasis transmission and control. Therefore, we also investigated the biomedical context of treating schistosomiasis and the social context of both accessing treatment and of schistosomiasis transmission. These are now looked at in turn.

ANTI-SCHISTOSOMAL PROPERTIES OF MALARIA TREATMENTS

It has been speculated that in co-endemic areas particular malaria treatments (the artemisinin derivatives artesunate and artemether) may have additional benefits for schistosomiasis control alongside praziquantel treatment. This could be significant in Moyo and Adjumani.

Although the number of studies on *S. mansoni* is small, it has been shown that repeated doses of artemisinin-derivatives in combination with praziquantel has a prophylactic effect in reducing the risk of *S. mansoni*, and some benefit for cure rates (Perez del Villar et al 2012; Utzinger et al 2000). Artemisinin has been incorporated into guidelines for preventing *S. japonicum* in China (Liu et al 2011). However, due to concerns over the development of drug-resistant malaria (ibid.) artemisinin is not recommended as a treatment or prevention strategy for schistosomiasis in co-endemic areas (as Uganda is). Outside of interventions and trials, the influence on schistosomiasis control of artemisinin derivatives used for malaria in co-endemic areas is not known, although it has been suggested that there are additional benefits (Caffrey 2007 p. 436, Keiser and Utzinger 2007, Perez del Villar et al 2012).

In Moyo and Adjumani Districts, artemisinin-based treatments were introduced as first-line malaria treatment in 2007 (discussed with Acting District Health Officer of the time). In the district hospital, where injectable artemisinin for severe malaria was not always available, quinine was still used. When oral treatment for malaria was required, 'Coartem' (artemether-lumefantrine), the tradename that the artemisinin derivatives were commonly known by, was widely used. In the districts, people sourced Coartem from government health centres or purchased it from private clinics. They used it as soon as symptoms interpreted as malaria began, with or without seeking advice from a health centre or clinic, with or without a positive blood test for malaria. In villages near the river, while Coartem had initially

been a drug that the VHT held, they reported that this was not the case anymore. However people were still able to access it from the local health centres and private drug clinics.

From the survey questionnaire, 79.6% of participants reported to have taken Coartem in 2013 (84.3% of participants in Moyo and 74% in Adjumani). The majority of participants reported to have taken Coartem twice or more in the preceding year (63.7%, with 4.4% of participants 'unsure' how many times they had taken it). In addition, 1.6% reported to be taking Coartem at the time of the survey, and 21.9% to have taken it in the preceding month. This high use of Coartem is in keeping with previous research on biomedicine use (Allen and Storm, 2012) and with ethnographic observations of healthcare seeking and management.

Therefore, while praziquantel use among participants in the cross-sectional survey was intermittent, normally once a year or less, self-reported Coartem use was higher. This was not only in terms of the proportion of participants who had taken it in the preceding year, but in addition, it was often taken multiple times per year by a large proportion of the participants. If artemisinin-based compounds do have an additional impact on *S. mansoni* control in co-endemic areas, the high use of these drugs in addition to praziquantel distribution may have had a role in reducing rates of schistosomiasis. However, Coartem is used in other areas where malaria and schistosomiasis are co-endemic. Therefore, additional factors beyond the use of biomedicine are now considered.

MOVEMENT AND MOBILITY

In Uganda there has been praziquantel distribution for over ten years. Neighbouring South Sudan has not had a mass drug administration programme. Previous research carried out in northwestern Uganda, suggested that the

movement patterns across this border area may facilitate schistosomiasis control. In 2009, high rates of schistosomiasis were found in Panyimur market near Lake Albert and the border with the Democratic Republic of Congo (DRC). In this area, there was a large number of people from the DRC where mass drug administration did not occur who came to Panyimur for the market, which could explain the high rates of infection among those attending the market (both Ugandan and Congolese) (Parker et al 2012 p.111). However, in Moyo District that same year, as discussed previously, lower rates of schistosomiasis were found on a fishing island. In contrast, it was noted that very few people came to the sites from neighbouring southern Sudan where no mass drug administration occurred (ibid.). This could help explain the findings as all these fishermen, despite being on the island, had accessed the distribution of drugs at some point even if not yearly. The two sites differed however in other respects, one being a busy market setting, the other being a fishing island. There are also likely to be many factors influencing the transmission of schistosomiasis at these sites. Despite the difference in settings between the sites in Panyimur and Moyo, the contrasting findings are striking.

Do these movement patterns still hold? In Moyo District, there is a busy weekly market in Laropi, a trading centre along the river where people attend from neighbouring districts and South Sudan. However, in 2013 it was noted by some people including a market vendor I knew well that the market was not as busy as it had been five years previously. Certainly, the fishmongers we interviewed at the landing sites where we carried out the survey took their fish to sell in the market across the border in Nimule, South Sudan, or elsewhere rather than Laropi. Therefore, it may be that the movement patterns across this border area have influenced sustained low levels of schistosomiasis among those along the River Nile, as described by Parker et al (2012).

However, it is a dynamic situation. For instance, over a few weeks in December 2013, tens of thousands of refugees from South Sudan settled in Adjumani District. This impacted on the local fish business particularly at two of the landing sites nearest the settlements. These settlements grew quickly into bustling trading centres, and many women who had been engaged in the fish business at the landing sites sought other business at the settlements, such as preparing and selling cooked food. Subsequently, at one fishing site a few secondary school girls arrived to begin fishmongering, seeking extra money for school fees, clothes and household needs. This all occurred just after completing the parasitology survey, and so it does not in itself explain the findings. It does however highlight the delicate balance of schistosomiasis control and the possibility that the situation may well change.

Aside from cross-border movement, the everyday movement of people within the fish business has the potential to affect schistosomiasis transmission rates at the landing sites. The people involved in fishing-related activities waxes and wanes with seasonal changes in the fish catch and cultivation periods. One fisherman and local leader said:

“You see, these people are like the Karamajong [in Eastern Uganda]. The Karamajong, if there is nowhere to graze their cattle here, will move all the way up to Moyo and back. For these fishermen, some of them move all the way up that way or down that way. It depends where the fish are good. They may spend some days or weeks there, or come back daily.”

This was found in fieldwork when returning to a landing site for follow-up, the majority of those who participated in the survey were not there as they had moved to other sites, were taking fish to market, or were in their fields cultivating. This is likely to be significant for understanding the parasitological findings. For instance,

the woman identified with high intensity infection in the parasitological survey only used the one fish landing site, but spent part of the agricultural season in fields in the inland area of Adjumani District where foci of disease had been reported in health centre data. It is difficult to say at which site she contracted schistosomiasis. She did, however, report to have taken praziquantel in May 2013.

Understanding these movement patterns aids us in understanding the parasitological findings, both in terms of the overall low levels of infection across the population, and individual vulnerability. However, it does not fully explain the situation. We can hypothesise that prior to the survey at least broadly speaking, most movement across the border was from the landing sites to Nimule market. These broader patterns of movement might have enabled low infection levels (Parker et al 2012). On the other hand, people's movement within, into and out of the fish business means that local and widespread foci of disease transmission are highly likely to be linked. In addition, people not previously exposed to schistosomiasis or previously treated through the mass drug administration are more vulnerable to infection. This dynamic situation makes it extremely difficult to determine if this is the full explanation, or if the low levels of infection are sustainable over time. The following section therefore examines whether factors at the landing sites themselves have enabled low levels of infection.

WATER, SANITATION AND HYGIENE

Given the life cycle of *S. mansoni*, do aspects relating to water, sanitation and hygiene help explain low prevalence?

While access to safe water and sanitation reduces the odds of schistosomiasis infection (Grimes et al 2014), associations between water, sanitation and hygiene on schistosomiasis transmission are complex and depend on many contextual

factors (Grimes et al 2015). Even with improved access to safe water sources, preventing water contact completely is highly unlikely. Likewise, even with improved access to sanitation, due to the schistosome life cycle and replication within the snail intermediate host, even if a small number of parasite eggs release miracidia into the water, many cercariae are released from the snails that can go on to infect people in contact with the infested water (ibid.). Transmission can continue despite access to safe water and sanitation facilities unless water contact and open defaecation are prevented completely. This was not found to be the case at any of the landing sites.

A lack of regular access to, and use of, a safe water source (borehole or piped water) and sanitation facilities, was a common finding at many of the landing sites. The majority (eight) of the fishing sites did have latrine blocks, yet four had no access to nearby functioning latrines. At these sites everybody defaecated in the bush surrounding the village. At two of these sites, previous attempts at constructing latrines had failed with the structures quickly collapsing. Moreover, there are numerous small islands in the river. Some of these are for fishermen only (one is even called *Oko ajio*, meaning no women allowed), where they stay for a few days or weeks at a time. Others are busy fishing sites where both fishermen and female fishmongers stay. On these islands there are no sanitation facilities and when out in the river people reported to go in the reeds or the river.

In terms of safe water access⁷², at six of the landing sites there was no access to borehole or piped water, therefore people used water from the river for all purposes. Yet even at the landing sites where there was a nearby borehole, the river water was still used for certain activities. The cost of borehole water (which was paid as a monthly sum per household, typically 1000 Ugandan shillings) and the

⁷² Referring to borehole or piped water.

higher cost of piped water (which was charged per jerry can, somewhere between 100 and 200 Ugandan shillings) was one limiting factor for some people. In fact, there wasn't piped water near any of the landing sites we surveyed (at one site, there was a source of piped water at a nearby centre on the road, but this was about three kilometres from the landing site). At one site, the monthly borehole fee had not been paid, or collected. This normally goes towards borehole maintenance and is collected by a local water committee and organised through the sub-county. In this instance, the borehole was either often in a state of disrepair or locked until the maintenance fees had been paid. The time it took women to fetch water was another limitation for people using borehole water, especially for cleaning fish or washing clothes. Women often collected water from the river for cleaning fish and washing clothes, not least because of the ease and abundant supply of water for these activities. Many women also preferred the river water because it was softer than the borehole water, and therefore soaps better. All in all, even where people had access to borehole water at the fishing site, they still used river water for some purposes.

However, it is not people's access to a water source per se that is important for schistosomiasis transmission, but people's contact with potentially infested river water. Therefore, the key factor with water use is how this influences people's exposure to schistosomiasis through their contact with the river water, and not simply their access to water sources. Although the availability of nearby borehole or piped water will likely reduce people's contact with the river, as will be shown, it does not eliminate it completely. It is likely that the nature and degree of people's water contact influences infectivity, that is, if somebody has high infection load or low infection load. This is affected by the time of day of water contact, the amount

of time spent in the water, and the extent of their body surface area that is in contact with the water (Kloos et al 1997).

Swimming is thought to be particularly important for transmission in some cases. Higher infection rates are seen in younger age-groups, and it is suggested that eggs can be released into the water while swimming (discussed in Grimes et al 2015), and more often than not it is children swimming. This is an important clarification in Moyo and Adjumani. It was only at one of the Obongi sites we surveyed where children were often playing in the river. At one site, the young men reported to learn to swim before learning to fish, but at the majority of sites the fishermen did not swim. In fact, at the Madi sites we surveyed it was predominantly adults at the sites anyway. At some of the sites, young children were occasionally seen, yet at most sites this was rarely the case. Many sites were for the fish business. The fishers and fishmongers stayed at the fish landing sites, but their homes were in a village elsewhere where their children stayed with other family members. On one extremely busy island in the area, children were not allowed; a by-law had been passed, enforced by the Local Chairman and Beach Management Unit. Therefore, at the majority of fishing sites surveyed this was unlikely to be a major feature of transmission.

Studies have demonstrated that peak concentrations of cercariae in the water occur around midday and in the early afternoon (Kazibwe et al 2010). Although transmission can occur outside this, there is higher risk during this time period. At the landing sites, the general pattern of people's water contact depended on the activities they were carrying out. Typically, the fishermen went out to the river in the early morning (5-7 am) while women collected domestic water from 6 am. The female fishmongers arrived at the sites around 8-9 am and the men returned from fishing in the late morning or around midday. The female fishmongers remained at

the landing sites cleaning and gutting fish and the fishermen returned to the river to lay their nets in the late afternoon (3-5 pm). Some fishermen returned to land in the early evening (5-7 pm); while others remained in their canoes overnight, returning the next morning. They would take a piece of smoking firewood in their canoe to cook cassava and fish, and to deter mosquitoes.

Given these general patterns of the fish business at the landing sites, there was a tendency for people's peak river contact to be in the mid to late morning hours. This was when the fishermen returned from fishing and the fishmongers went to the boats to collect the fish. At a number of the fish landing sites people's contact with the river reduced in the early afternoon (when peak transmission is likely to occur). This was a time when the fishermen were resting and women were either preparing fish or had finished their morning work and returned home. At many sites though, people had contact with the river water throughout the day.

Having said that, while people had contact with the river water at every fishing site a lot of it was in fact avoided and brief if it occurred. This may limit vulnerability to high infectivity with schistosomiasis. The fishermen often stepped to the canoe, or took only a few steps in the water to push out or pull in the canoe. The women often made repeated but short trips into the river collecting water for cleaning fish, or washing clothes.

While some generalisations have been made in the discussion so far, it was also clear that there were large variations in people's contact with the river water. This could be seen between people, across the day, between sites, and across the year. This makes generalisations extremely difficult, apart from to say that people at every site had contact with the river water. At sites where the fish catch had depleted, activities at the sites reduced and therefore people's contact with the river reduced. On the other hand, during the rainy season that began in late March

or April, the river swelled and the landing site water levels rose. The paths to and from the landing became water logged, and people had no choice but to wade, sometimes waist deep, out to canoes.

Additionally, at some sites female fishmongers tended to have more prolonged water contact immersing themselves sometimes thigh deep in the landing site water when collecting fish from canoes. The hustle and bustle collecting fish, competition between fishmongers, and the weight of the basins of fish meant that women appeared less cautious in avoiding water contact than the fishermen. At one site though, it was the male fishmongers who had more prolonged water contact. At this site, a few male fishmongers spent long periods of time (sometimes an hour or more on and off) waist deep wading in the landing site water while waiting for canoes to arrive early in the morning. At another site, the women often spent ten to twenty minutes bathing in the landing site water in the hot afternoon hours. The woman who had had a high intensity of schistosomiasis infection came from this site.

It is difficult to generalise about water contact and its impact on levels of schistosomiasis among people along the River Nile. Certainly there are aspects that could perhaps limit high intensity infections, such as if people's contact with the water is early in the morning, limited in time and limited in the extent of their immersion. However, we can see that this is not always the case, and across all the sites people continue to have daily contact with the river water for various reasons.

One feature across all the sites was their domestic nature compared to the urbanising sites along Lake Victoria that are described in the literature (Beuving 2010). While the sites predominantly revolved around the fish business, they were also used for many domestic tasks. The river was sometimes the main water source for a village, but it was also the main water source for the female fishmongers who

often carried out their domestic tasks such as washing clothes while waiting for the fishing boats to land. With this, soap was commonly used at the landing sites and during some of people's contact with the river water. This may be a significant factor for schistosomiasis control.

Soap use during water contact is thought to provide some protection against schistosomiasis due to its toxic effect on the *S. mansoni* cercariae (reviewed in Grimes et al, 2015). In fact, a retired doctor in Adjumani who owned a private health centre outside of the main town, and had received higher degrees in Europe including the UK, discussed his recollection of schistosomiasis control in the district. He discussed the various control measures that had been used in the past, such as copper sulphate as a molluscicide for snail control. He went on to say:

“Another observation of mine is that in areas where there are the soap suds from washing, the snails actually avoid these areas. So I used to advise people to rub soap suds on their legs before entering the water”
[interviewed 27.08.2013]

There is some suggestion that soap acts as a molluscicide, but its greater effect is on the cercariae (Grimes et al 2014, 2015). While we didn't observe the practice that this doctor described during the fieldwork, at the fishing sites women carried out their domestic chores including washing clothes and utensils with soap, and soap was also used as fish bait on hooks. Women would often spend the hours waiting for the fishermen to return to land, washing clothes. This is likely to have some effect on cercariae present in the water. Therefore, it is likely that this use of soap mitigates some risk of schistosomiasis, despite people's ongoing contact with the river water.

Overall, certain aspects of water, sanitation and hygiene practices may therefore mitigate *S. mansoni* transmission. Yet water contact and open defaecation continue suggesting that transmission is unlikely to have been halted completely by these measures alone. This is the case for all the aspects discussed in this chapter, the use of biomedicine, people's movement patterns, and water, sanitation and hygiene practices. The main points that I want to draw out from this discussion is that taken together these biosocial factors likely sway towards enabling low levels of infection and reduced transmission. Therefore, the parasitological findings can only be investigated through an interdisciplinary approach and understood by situating them within this biosocial context.

A BIOSOCIAL APPROACH TO UNDERSTANDING SCHISTOSOMIASIS CONTROL

I first want to reflect on the methodological approach before discussing the implications of the findings discussed in this chapter.

The social aspects of neglected tropical diseases have arguably been neglected in research (Allotey et al 2010), yet there are demonstrable strengths of integrating anthropological and social analysis into both the research process design and implementation of neglected tropical disease control programmes (Allen and Parker, 2012; Bardosh et al 2014). This biosocial approach, combining multiple methods of inquiry, is particularly pertinent for neglected tropical diseases, but also for the field of global health more generally (Farmer et al 2013). While chapter two discussed some of the difficulties encountered in such an approach, this chapter has demonstrated the value of applying an ethnographic-epidemiological approach to understanding low levels of schistosomiasis among fisherfolk.

Using a mixed ethnographic-epidemiological approach allowed an in-depth exploration of the complexities of schistosomiasis control in Moyo and Adjumani.

Methodologically, this had advantages. Doing ethnographic research proved to be useful for building trust and rapport, which was especially important for aspects of the study such as recording detailed water contact observations. However, the parasitological survey also played a crucial role in this. Some people were dissatisfied at taking tablets from the free distribution without knowing if they had the disease or not it. "To know your status" was important for people. In a conversation with a female committee member at one of the health centres near the river, she explained to me:

"These people along the Nile belt are really suffering with these diseases, they cannot avoid them. You see them every day at the river. Is your programme going to continue?" I explain it will not, but the mass drug administration programme will. She continues, "But we need the testing too, not just the drugs. You need to see it with the microscope; you cannot see these things are there just with the naked eye." [19.06.2014]

People living and working along the river had limited access to testing ordinarily, as at the majority of sites the nearest health centre did not have microscope facilities. Treatment provided at these health centres was based on clinical judgement. People were diagnosed with 'intestinal worms' commonly treated with metronidazole and ciprofloxacin for other intestinal infections, or albendazole for hookworm and other soil-transmitted helminths. The distance, time and financial costs deterred many people from attending a health centre further away that had laboratory facilities. Therefore, there was a demand for the parasitology survey to be carried out at the landing sites and overwhelmingly people welcomed the programme.

Returning to the main question, is mass drug administration successfully controlling intestinal schistosomiasis in northwestern Uganda? Mass drug administration is likely to have had an impact on the low levels of infection seen among fisherfolk. Certainly in examining the parasitological results using the survey data alone, mass drug administration appears to be the key factor that explains the results. But this arguably oversimplifies the complexities of disease control. Furthermore, it still leaves the question of why it has been successful in this setting given the difficulties found elsewhere, and given the inconsistent distribution and uptake of mass drug administration. Using an ethnographic-epidemiological approach this chapter has demonstrated that the answer to understanding low levels of infection is much more complex than it first appears. It is likely that in this area it has been enabled by a number of factors that influence vulnerability to schistosomiasis infection. Each factor alone cannot fully explain the low levels of infection, but understood together they show how this context may have led to the promising results.

As has been shown, while mass drug administration is generally sought after in this area, the actual distribution and consumption of praziquantel is inconsistent. However, there are additional immunological effects in adults that help protect against infection, and with the widespread use of Coartem for malaria, these biomedical factors may have had additional effects on levels of infection of schistosomiasis. Again, these factors alone are unlikely to explain the parasitological findings, as praziquantel distribution and artemisinin use for malaria occur in other settings where schistosomiasis control has been less successful.

Therefore, other factors have been considered. Firstly, the movement patterns of people within and around this border area may have been favourable for schistosomiasis control, with the majority of cross-border movement being of people from Moyo and Adjumani travelling to towns in South Sudan for work

periodically. Findings also suggest that movement in this dynamic border area may affect disease control. Recent insecurity in South Sudan has led many people to flee into Adjumani district. With this, at some fishing sites, people moved from the fish business to other businesses at the refugee settlements. Subsequently, new women moved into the fish business. By itself, it is difficult to say with confidence that this is the key factor, as the movement patterns are so dynamic.

Consequently, the pattern of infection found in the parasitology survey may well change with changing patterns of movement and migration in relation to the border and the fish business.

At the landing sites themselves, water, sanitation and hygiene practices are significant for schistosomiasis transmission and control. While only three people were found with *S. mansoni* in the survey, people were often diagnosed with other intestinal diseases linked to water and sanitation. *E. coli* and *G. lamblia* were commonly found on stool microscopy at local health centres and often the infections people were treated for when they attended with intestinal symptoms. In addition, in 2014, there was a cholera outbreak in Obongi Town along the river. It is evident that water, sanitation and hygiene are still significant problems for public health in this area.

In particular for schistosomiasis, water contact and open defaecation continue to occur and are unlikely to be halted completely despite improvements in water and sanitation. This is not to suggest that these structural improvements would not have an impact (as discussed in relation to cholera they will likely have much broader impacts from a public health perspective), but to further point out the limits of single approaches. However, in terms of water practices, women's high use of soap at the landing sites, which are also used for many domestic purposes, may be having a protective effect against schistosomiasis in some cases. Therefore,

there are a number of biosocial factors that are likely to have contributed to the low levels of infection seen.

It is in fact extremely difficult to obtain a clear picture of what has enabled a reduction in levels of infection. Having spent a year in the districts and at the various landing sites, it is still difficult to say confidently. Partly, as explored in this chapter, this is because of the local complexities of schistosomiasis transmission and vulnerability to schistosomiasis, which is influenced by many biological, social and environmental factors interacting with each other.

But it is also because there is limited background data. As discussed, rapid mapping prior to the introduction of mass drug administration was determined by assessing parasitological samples among select primary schools. These findings were then extrapolated to determine whether mass drug administration was to be introduced, and whether it was to be for the primary school only or include high risk populations including fishing populations (Gill and Beeching, 2011). In Moyo and Adjumani, in addition to this there is limited data available through the public health system, which has meant that there is very limited data on disease rates in adults in the recent period prior to the introduction of yearly community-wide mass drug administration. While there have been some surveys carried out through Vector Control Division, the mainstay monitoring of mass drug administration is based on measuring the uptake of praziquantel. This in itself has been problematic in some areas. From research in Tanzania, Allen and Parker have suggested that there is danger of misreporting, of overinflating uptake figures due to concerns that low figures would jeopardise continued donor support (Parker and Allen 2013; Parker and Allen 2014). These factors are largely influenced by global health perspectives on schistosomiasis and neglected tropical diseases with the roll out of one size fits all public health interventions, being largely based on the availability of

free drugs (Bruun and Aagard-Hansen, 2008). This is a point I will return to in the concluding chapter.

Despite these critiques, it is encouraging that so few cases of intestinal schistosomiasis were identified among the fisherfolk. This may well be an area to focus for elimination. The global health agenda is shifting from an endeavour to reduce morbidity and control transmission, towards eliminating schistosomiasis 'as a public health concern' and ultimately eradicating transmission (WHO 2013). In Moyo and Adjumani, mass drug administration has been the only substantive public health intervention for schistosomiasis, but despite the success, arguably more needs to be addressed. Just as there are factors that have enabled control, there are also factors that may tip the balance and enable resurgence in infection. There are undoubtedly limitations with relying solely on mass drug administration for sustained schistosomiasis control.

Beyond mass drug administration, it has been demonstrated that a combination of control strategies is needed for sustaining control of schistosomiasis, particularly in areas of low transmission (Grimes et al 2015; Rollinson et al 2013). One aspect of this is snail control. For landing sites in Moyo and Adjumani, are they still potential transmission sites? To answer this would require an investigation of the environment, local ecology and snail biology. Historical data on schistosomiasis in this area demonstrates that transmission did occur, although micro-geographical variations mean it is difficult to determine at which particular sites. Transmission depends on the presence of the snail intermediate host, and environmental changes affect snails and their habitats. Certainly, environmental changes have occurred. The river and its banks are always changing with aquatic plants, such as water hyacinths, overrunning some landing sites. There are also seasonal and long-term changes in river flow and depth. For instance, flooding in the early 1960's led

to the river level rising. More recently, following a period of drought in 2005/2006 water level and flow decreased in this section of the River Nile (data kindly provided by Uganda Ministry for Water and Environment). These factors are undoubtedly significant in schistosomiasis control, and would be an important area for further research.

There are limitations to the research which should be noted. Whilst the current recommendation for mapping areas for mass drug administration and an approach used in many studies, in low transmission areas low intensity infections⁷³ may be missed by the Kato-Katz method used in this survey (King 2010). However, the methods used were appropriate at the time and in accordance with the methods used by Vector Control Division for assessing rates of infection in the community.

In line with the broader research, the survey only included adults. At the majority of sites people in the fish business were adults, with a few exceptions. At one site, males began fishing from an early age (seven years onwards). In addition, at another site some females left school aged 14 or 15 years and spent more time at the landing sites collecting water, washing clothes, or beginning the fishmongering business. Further assessment extending to include younger age groups would therefore be needed to determine the extent to which *S. mansoni* infection has reduced across the general population along the river.

CONCLUSION

⁷³ Recent research by Lamberton et al (2014) reported a sensitivity of 74% for two Kato-Katz smears at six months post-praziquantel. One recommendation is to analyse six Kato-Katz slides per person, i.e. two slides per stool from three samples. In Moyo and Adjumani this approach was not possible within the scope of the study, time and financial constraints. The other recommendation is to use urine antigen testing for monitoring and evaluation (ibid.). This was not an available method for the study.

Could it be that the culmination of the biomedical and social factors, as explored in this chapter, have leant towards mass drug administration being effective in reducing levels of infection among adults in this area? It is highly speculative, given the complexities of analysing a real life situation. The everyday complexities are what make people vulnerable to neglected diseases, are what make public health programmes not work in certain areas, and arguably as we have seen in the case of schistosomiasis in Moyo and Adjumani, are what enable success in other areas. The sustainability of this is yet to be seen.

This chapter has explored the social and structural drivers that enable and mitigate biological risk in this biosocial context, going beyond mass drug administration. It is likely that mass drug administration has had an effect in reducing levels of intestinal schistosomiasis infection among fisherfolk in northwestern Uganda. However, using an ethnographic-epidemiological approach, this chapter has demonstrated that this success is likely due to a number of factors that interlink and influence social vulnerability and biological risk. There has been much critique of 'one size fits all' approaches to global health issues and disease control, however within the context described in this chapter, mass drug administration has arguably had an effect in reducing levels of infection among adults along the river. The majority of people, having observed the reduction in disease, trust the benefit of the programme, even if they do not always trust the actual delivery and distribution of it.

With schistosomiasis reducing, what public health concerns affect people along the river? The following chapter discusses another neglected tropical disease, Buruli ulcer. Unlike bilharzia, there has been a limited public health response, but as will be shown, healing strategies have long been in place.

5. BURULI ULCER: AN EMERGING PUBLIC HEALTH CONCERN?

'What do you know about Buruli ulcer?' a hospital doctor asked, when discussing plans for the schistosomiasis parasitological survey. He rarely saw the condition in the hospital but, *'deep in the village, it was found to be there'*. Later on, a few people in the survey questionnaire reported that they had had Buruli ulcer and all had been treated by local herbalists. When I asked one of the survey team about this they replied, *'Yes, you see, these people, they have their local herbs that treat Buruli'*, a treatment that involved making cuts to the skin and applying local herbs.

Investigating further, it became clear that for people living and working along the river it was a well-known affliction. People's knowledge of *Buruli*, as it was commonly known, had been informed from experiences over generations. With this, there has been some adoption of and merging with particular biomedical practices and understandings of the disease, but predominantly people continued to use the treatment that they knew and trusted from local herbalists, treatment that had been performed for generations.

Elsewhere though, Buruli ulcer has been described as a 'disease emerging from obscurity' (Wansborough, 2006). In fact, following a visit to West Africa in 1997, Dr Hiroyoshi Nakajima, then Director General of the World Health Organisation (WHO), declared Buruli ulcer an emerging disease⁷⁴. Identified as a neglected disease of significant public health concern, the Global Buruli Ulcer Initiative was launched in 1998 under the directive of the WHO. It had been known about at least since the early twentieth century. However, the framing of Buruli ulcer as an emerging public health concern and as a neglected tropical disease has enabled the disease to be re-

⁷⁴ <http://www.who.int/Buruli/gbui/en/>

recognised and spoken of within global health. Buruli ulcer is an emerging public health concern from a global health perspective, yet personal histories revealed that it had long been known about in the villages along the River Nile. For people living in this area it was far from emerging.

What has shaped these responses to Buruli ulcer that we see today? How is it that the framing of Buruli ulcer from a global health perspective differs so greatly from local understandings of the disease? People's responses to Buruli ulcer are shaped by perceptions of the efficacy of treatments and trust in treatment providers. Exploring local responses to Buruli ulcer illuminates what is hidden from a biomedical perspective on the disease.

This analysis draws on fieldnotes, interviews and discussions at the landing sites and with healthcare providers. Twenty-one interviews were carried out with people who reported to have suffered from ulcers known as *Buruli*. In other interviews people discussed forms of local poisoning. Two cases of local poisoning in particular may well have been a form of Buruli or tropical ulcer. Interviews were held with four herbalists who treated Buruli. The disease was also discussed with staff from the district health team and local health centres. In addition, it was one of the topics covered in discussions with men and women at each landing site. The majority of the discussions and interviews on Buruli ulcer were with Madi people, therefore I tend to use the Madi terms for the disease and its understanding, but I highlight the differences for people in Obongi where appropriate.

The following section outlines the key features of Buruli ulcer, its history, transmission, clinical features and public health policy. The second section discusses how Buruli is perceived, understood and managed by people living along the River Nile in Moyo and Adjumani. This demonstrates the knowledge that has

been learnt and acquired, that continues to develop and influence healthcare choices today. It demonstrates how the longevity of the disease and its management has fostered trust in local herbalist's treatment. This is not only through the perceived efficacy of the herbalist's treatment, but as discussed in the third section, also through the perceived inefficacy of biomedical treatment. The final section concludes by examining the divergences between global health and local perspectives on Buruli ulcer, how these discrepancies arise, and how they are continued unquestioned. It reflects on the framing of Buruli ulcer as an emerging public health concern and a neglected tropical disease, and what it means from a global health perspective, within the districts, and by the people that Buruli ulcer affects.

BURULI ULCER

Buruli ulcer⁷⁵ is an ulcerative skin disease caused by *Mycobacterium ulcerans*, a bacteria in the same group as those which cause leprosy and tuberculosis. It can cause severe long-term complications due to the destructive nature of the ulcer (the tissue destruction occurring from a toxin released by the bacteria). Those affected tend to be systemically well, but some lesions are more aggressive than others⁷⁶. Depending on the site of the lesion, permanent damage such as scarring and contractures can occur, even destruction of underlying bones. The disease may recur, which is thought to be much more likely than reinfection (Debacker et al 2005). It has however, been estimated that one third of early lesions, particularly nodules, resolve spontaneously (Wansbrough-Jones and Phillips 2006).

⁷⁵ A number of reviews on advancements in the understanding of Buruli ulcer and its management have been written (e.g. Wansbrough-Jones and Phillips 2006; Merritt, Benbow and Small, 2005; Sizaire et al 2006).

⁷⁶ Especially the case for ulcers with associated oedema.

Like other neglected tropical diseases, Buruli ulcer is associated with areas of poverty, with limited access to safe water sources, limited basic medical care, limited access to healthcare and low levels of education (Duker, Portaels and Hales, 2006 p.569). It primarily affects rural areas in certain countries in Africa including Uganda, and although the exact mode of transmission is unknown, it is found especially among people involved in farming near groundwater and slow flowing rivers such as areas along the River Nile. The distribution of the disease therefore overlaps with schistosomiasis.

Buruli ulcer was first identified in Australia in 1948 and named Bairnsdale ulcer (MacCallum et al 1948). From 1961 these ulcers became known as Buruli ulcer after the area of the same name in Uganda near Lake Kyoga (now Nakasongola District) where many cases were reported (Clancey et al 1961, cited in Morrow, 1975 p.17, see also Clancey, Dodge and Lunn 1962). In the 1960's and 1970's, the Uganda Buruli Group described the pattern of Buruli ulcer among recent refugees from Rwanda who settled near the River Nile. Interestingly, new cases ceased when the refugees moved to other areas, leading to the hypothesis that the disease was transmitted along water bodies, the rivers and lakes (The Uganda Buruli Group, 1971). Barker (1972, 1973) also associated the disease along the River Nile in swampy areas that contain a particular type of grass vegetation⁷⁷. He reported that in Madi areas, "on the west side of the river [Moyo district], where the land is hilly, the disease is confined to the river's edge; but on the east side [Adjumani district], where the land is flatter, the disease extends up to 10 miles from the river" (Barker 1972, p.43). He went on to suggest that Buruli disease spread and became endemic in areas of Uganda along the River Nile after floods in 1962-64 created new sites of

⁷⁷ *E. pyramidalis*

permanent swamps⁷⁸. In other places outside Uganda, Buruli ulcer has since been associated with flooding and other environmental activities that affect water bodies such as deforestation (Duker, Portaels and Hale, 2006; Merritt, Benbow and Small, 2005).

Transmission appears to be seasonal (Duker, Portaels and Hale, 2006). In Uganda, particularly among males and infants, transmission was found to decrease during the dry months and increase when the rainy season began (Revill and Barker, 1972). Transmission was steadier across the seasons among females, attributed to the fact that women collected water from permanent swamps throughout the year (ibid.).

It is thought that it may be transmitted⁷⁹ through small cuts from local grasses or other minor wounds, associated with exposed skin when farming and wading in rivers. In that respect, leg and arm lesions are particularly common with trunk lesions more common in males than females⁸⁰ (Raghunathan et al 2005). Other associative factors have been difficult to ascertain due to confounding socioeconomic factors that are also associated with exposure. For instance, some case-control studies, have found that using soap for washing is associated with a decreased risk of Buruli ulcer (ibid; Nackers et al, 2007). In one study, those in the control group (the un-infected group) were more likely to use soap and antibiotics for managing injuries and wounds, and to attend the health centre for injuries

⁷⁸ Barker found from the field surveys no history or scars that suggested the onset of Buruli from more than 10 years previously, i.e. pre 1962 flooding (1972, p.872). However, Clancey, Dodge and Lunn in 1962 reported four active cases from Moyo in Madi; and Lunn et al in 1965 report finding 'burnt out cases' (p.279) suggesting earlier infection that had resolved.

⁷⁹ *M ulcerans* has also been identified in the salivary glands of certain biting water insects leading to the hypothesis that it is transmitted through the bite of such insects. However, it is also found on their body surface and so transmission may be mechanical. In addition, it has been found in certain snails and small fish, although the significance of this in transmission to humans is not known. (Duker, Portaels and Hales, 2006).

⁸⁰ Possibly due to exposed skin when farming, while wearing a shirt while farming is a protective factor.

(Nackers et al 2007). However, in another case-control study treatment of wounds with soap was identified as a risk factor, whilst rubbing alcohol was protective (Pouillot et al 2007). It is likely that these inconsistencies can be explained by complex interactions between the biological risk factors and social vulnerabilities associated with Buruli ulcer.

Currently, the vast majority of cases are found in Africa, particularly West Africa where it is highly endemic. Recent research on Buruli ulcer has therefore predominantly been carried out in West African countries and while there is some social science literature on Buruli ulcer, this remains limited and cannot be readily applied to northwestern Uganda⁸¹.

Since 2002, cases have been reported to the WHO. Table 1 shows the number of cases in Uganda reported per year in relation to the number reported in Africa and globally (adapted from WHO⁸²). Data since 2010 has not been reported for Uganda, but previously the numbers were low.

⁸¹ There are shortcomings in applying these findings to the work presented here. Most of the research in West Africa has been carried out by identifying cases from hospital settings and not from community settings. However traditional herbal treatments are a common option especially in rural settings in Africa, and the use of traditional healing and local herbs for the treatment of Buruli ulcer has been documented across a number of areas. Therefore, results of studies identifying cases through the formal health system are biased towards those who have accessed hospital treatment.

⁸²http://apps.who.int/neglected_diseases/ntddata/Buruli/Buruli.html

Year	Number of cases reported, Uganda	Number of cases reported, Africa	Number of cases reported, Global
2002	117	2632	3269
2003	10	2954	3353
2004	7	5867	5954
2005	72	4674	4748
2006	5	5265	5377
2007	31	4935	5035
2008	24	5079	5156
2009	3	5029	5084
2010	Data not reported	4846	4912
2011	Data not reported	3845	4009
2012	Data not reported	3104	3215

TABLE 2: NUMBER OF CASES OF BURULI REPORTED TO WHO EACH YEAR

However, it is questionable how accurate this data is in representing the true picture of the burden of disease as many cases are likely to go unreported. Indeed, in 1999, a national case search in Ghana alone identified 5619 patients with Buruli ulcer lesions of different stages, with 3725 patients having active lesions and 1894 with healed lesions (Amofah et al, 2002). This is a substantial number, given the figures in table 2 which show that in 2002 to 2012, between 2632 and 5867 cases were reported each year from Africa as a whole.

One of the difficulties is in biologically diagnosing the disease. For suspected cases of Buruli ulcer, the recommendation is laboratory diagnosis, but in practice a clinical diagnosis is made based on the presentation and exclusion of other forms of skin

disease and illness. Certain antibiotic⁸³ regimes have been found to be effective, and therefore the current recommendation for treatment⁸⁴ of early lesions is a combination therapy of drugs used in the treatment of tuberculosis (rifampicin and streptomycin) for eight weeks. For more severe lesions, amputation of the limb is sometimes needed. However, hospital facilities that can manage these cases are not always available or easily accessible in rural areas where the disease tends to occur.

In Uganda, national policy on Buruli ulcer comes under the Ministry of Health, with a Buruli Ulcer Advisory Group. As a neglected tropical disease (NTD), it also technically comes under the coordination of the regional and national NTDs division. However, in contrast to other neglected tropical diseases such as intestinal helminths (worms), onchocerciasis (river blindness), human African trypanosomiasis (sleeping sickness) and lymphatic filariasis (elephantiasis), there is no specific programme for coordinated control, outreach or case finding for Buruli ulcer in the districts. Management is through the national health system, and relies on self-presentation of patients to the hospital, or referral through the system from the Village Health Team (VHT) to a health centre (grade II, III, IV) to the district hospital and if needed to a referral hospital (which for Moyo and Adjumani is either Arua, Gulu, Kampala).

One district staff member in Moyo was confident that this referral system worked well for Buruli ulcer. The VHT were advised to report and inform the health staff of

⁸³ The current WHO treatment recommendations are:

1. A combination of rifampicin and streptomycin/amikacin [also used for tuberculosis treatment] for eight weeks as a first-line treatment for all forms of the active disease. Nodules or uncomplicated cases can be treated without hospitalization.
2. Surgery mainly to remove necrotic tissue, cover skin defects and correct deformities.
3. Interventions to minimize or prevent disabilities.

Taken from: <http://www.who.int/Buruli/en/> [accessed 26.02.2014]

⁸⁴ Previously, the mainstay treatment was surgical excision and skin grafting.

'wounds that don't heal', and to 'monitor and inform' the health authorities of local herbalists treating such cases [Interviewed 30.01.14]. However, another district staff member reported that:

"Cases of Buruli only come to the district when they are necrotic; otherwise they use local herbs ... People locally know there is no treatment in the hospital ... so early diagnosis is a problem." [Interviewed 30.01.14].

Reliance on self-referral, with no specific outreach education or case-finding, means that self-presentation of people with the disease to the public health system relies on people's own understandings, perceptions and knowledge about Buruli ulcer and its management.

BURULI IN MOYO AND ADJUMANI DISTRICTS

People rarely presented to the health centre for suspected Buruli ulcer and there is very little documentation of the diseases in the districts. One health centre near one fishing site was managing an active case of Buruli ulcer. Another reported to have seen a case in the previous year. But otherwise, it was rarely diagnosed at the health centres. On the other hand, when we spoke with local herbalists they reported seeing cases of Buruli every year or every two years. One even suggested he saw somewhere between two to seven cases per year, including in the previous twelve months. Of those people who reported to have had Buruli ulcer, one had begun in the 1960's, five were from the 1970's, five from the 1980's, eleven from the 1990's, four from the 2000's, and a recurrence that occurred in 2012 and 2013. In addition, a male elder described a case of wound that took over a year to heal on his lower limb in the 1960's, but this was explained by him as a form of poison, distinct from Buruli.

There is some historical data on Buruli ulcer in this region. Similar ulcers were described in Uganda and Zaire (now Democratic Republic of Congo) in 1897 by Sir Albert Cook (Wansbrough-Jones and Phillips 2006), and later in the early twentieth century by Kleinschmidt⁸⁵. Clancey, Dodge and Lunn (1962) reported 50 patients, 32 from Buruli County and four from Moyo in Madi areas. Lunn et al (1965) found the disease to be distributed along the River Nile in areas of low population density (ibid. p.287). They reported 48 cases in a three and a half month period, and identified 39 new cases, of which 29 were active ulcers (ibid. p.279). In 1970, Barker (1972) conducted a field survey in Madi District (as Moyo and Adjumani Districts were then known) for active case finding. In ten communities in Madi District, 21 new cases of Buruli ulcer were identified (p.868). Overall, in Madi District in 1970, there were 49 new cases of Buruli disease identified, occurring in seven sub-counties (p.869).

In their study, Lunn et al (1965) noted the local term used was “juwe okoro” or “bile okoro” which meant roughly “the sore that heals in vain” (ibid. p.278). At some point, the local term changed, and these ulcers became commonly known as ‘*Buruli*’ in Madi. Most people, including elders and herbalists we spoke to who grew up in Madi region in the 1950’s and 60’s, only ever recalled the name *Buruli*. However, one herbalist born in the 1920’s recalled that when he was learning to become a herbalist the wound that is now known as *Buruli* was called ‘*macodo*’⁸⁶. He described this as ‘a boil which swells bigger and is more serious’. He reported that it was treated in the same way that *Buruli* is treated by local herbalists today. Another herbalist, born in 1939, recalled:

⁸⁵ Kleinschmidt found the ulcers to be infected with Acid-fast bacilli, similar to tuberculosis.

⁸⁶ ‘*Macodo*’ is translated as ‘abscess’ in the ‘Ma’di-English Dictionary’, Comboni Missionaries, 1995 (translated from the ‘Ma’di-Italian’ dictionary compiled in 1941 by Father Luigi Moizi).

Buruli was previously called 'jue macodo'. This was the same disease; the same treatment. There are two types of jue: jue [boil] and macodo [Buruli]. It was the medical people who brought the term 'Buruli'; I can't remember which year the name changed. When the name came, it was thought to be a different sickness. So people would go to the medical for 'Buruli' ... [He refers to a woman from the area] They were treated there at the medical and it went to losing their leg, and then the people started to say, 'but it is nothing but jue macodo, except the mzungus [White's] call it Buruli'. So those who saw the experience of this person here started going back to the herbalists. [Interview with male herbalist, 75 years old; 27.02.2014]

The disease has therefore been known by people in the area for a long time. There were previous names in the Madi language, but now it is commonly known as '*Buruli*'. In Obongi County, among those who are not Madi, they use the term '*lupi lupi*' (pi = a swelling; lu = adjective suffix), a term which was understood by all the different language groups, including Madi, although the Madi tended not to use it having adopted the common biomedical term.

The term '*Buruli*' is used for certain types of ulcers and oedematous swellings. Other lesions were differentiated from *Buruli* and required different herbs for treatment.⁸⁷ Nodules or boils were called '*jue*'. One specific type was *jue logbwiri* described as multiple nodules occurring in the armpits. Wounds that occurred especially on the feet (which could possibly be other forms of tropical ulcer) were also differentiated from *Buruli* ulcer.

Other forms of ulcer and skin disease have been endemic in northern Uganda, for instance yaws (Vaughan, 1991). Vaughan describes how during treatment

⁸⁷ *Jue* requires one cut and the application of herbs; all require different herbs.

campaigns by the British protectorate administration, yaws was initially not distinguished from the similar sexually transmitted infection, syphilis and associated with colonial concerns over control of sexuality in Buganda (central Uganda). However, yaws was more commonly the diagnosis in northern Uganda (p.138). In a report from a 1927 sleeping sickness campaign in Moyo, it was reported that there was a “great number of cases of Yaws and Ulcers that came up for treatment”, with the ulcers being described as “often repulsive”⁸⁸. In two months in Madi, they gave nearly 2000 injections for yaws and ulcers. During fieldwork, an elder described a disease that ‘bent the bone’ which he differentiated from the lesions seen in Buruli. This may well have been yaws; although he reported that it hadn’t been seen for a long time.

We cannot be certain from retrospective accounts of the biomedical causes of the swellings and ulcers discussed by people as *Buruli*, as many of the cases we discussed were not diagnosed bio-medically. As will be shown, people’s experiences and understandings of Buruli ulcer largely overlap with the different biomedical presentations of the disease. Historically, in the 1960’s and 1970’s these ulcers were biomedically identified as Buruli ulcer. We cannot confirm but perhaps some of these ulcers were defined as yaws earlier in the twentieth century. However, it is *Buruli* that has been adopted in the vernacular by the Madi to encompass some types of ulcers, and as demonstrated above, different types of swellings and ulcers are differentiated. Local understanding is that these ulcers and nodules are *Buruli*, and this is how they are identified by people. Since my purpose is to describe and understand the people’s perceptions⁸⁹, understandings and management of Buruli ulcer, whether or not the ulcers reported were truly Buruli

⁸⁸ Entebbe archives material kindly provided by Tim Allen. ‘Report on Tour in Madi April – June 1927’.

⁸⁹ See also Hausmann-Muela et al’s work on malaria, 2002.

ulcer is less relevant. In this chapter, I will use the italicised *Buruli* to distinguish the use of the term in the vernacular.

UNDERSTANDING ULCERS

When discussing *Buruli* with the herbalists or with people at the landing sites we showed a poster of the different Buruli ulcer lesions. It was a WHO Global Buruli Ulcer Initiative poster I found in one of the hospitals. I had initially seen the poster folded up in one of the clinic rooms, but when we went to find it, it was no longer there. We visited the wards and often the response was, 'I have seen the poster around', 'but it has been taken down', or 'perhaps it is in another ward'. Eventually we found one hidden away in a cupboard among a pile of papers. It had one corner missing (which had shown pictures of people who had scars from old Buruli lesions), however, it was still useful for our purposes.

In order to begin discussions and see how people understood these different forms of ulcers and skin lesions, we presented the poster to people as different forms of ulcers that people experience, not specifically Buruli ulcer. Referring to the poster, for the nodule, with the exception of one woman who stated that her *Buruli* had been like that, all stated that this was *jue*⁹⁰, a boil. The papule was rarely commented on, apart from one person who reported it could possibly be *Buruli*. People identified plaques and non-ulcerative oedema as *Buruli*, with some reporting that their ulcer had begun like this. Both pictures of early ulcer people identified as *Buruli*. On two occasions, the early ulcer with indurated edges was identified as cancer. Yet on the whole, early ulcer was the type of Buruli ulcer that people had suffered. On many occasions this was the wound that developed after a herbalist had made cuts. Late ulcer was also identified as *Buruli*, particularly when it had not

⁹⁰ Or the equivalent in the local language.

been treated in time. In a few instances, people asserted that late ulcer was associated with a form of local poisoning, 'erua hwe', but this was an exception rather than the norm, as will be discussed later.

Despite many uncertainties surrounding the cause of *Buruli*, explanations generally took on biomedical understandings of disease. One of the herbalists stated:

What I think is that there should be the worm which is got in muddy places when there is a lot of dew, where the germ [the herbalist corrects the English translation and says 'bacteria'] survives. You go there, you are affected. Mostly it is along the big rivers. Up like this you don't get so many people affected. [Male herbalist, 56 years old; Interviewed 07.02.2014]

This herbalist drew on detailed biomedical understandings of bacteria that he had learnt through school and from discussions with biomedical healthcare workers. Although not always as specific, many people, while unsure, used ideas of worms (*obu*) to explain *Buruli*. Many people also supported the deduction that it was found along the rivers or in muddy places. A few people recounted how it came from Buruli district in Uganda and was transmitted by the River Nile to this district:

What I have realised is that there is a clan in Western Uganda called Buruli. They used to suffer with this sickness. The story is that they washed this wound in the river and so possibly the worms travel in the water to here. Possibly you get it like that; maybe from drinking the water. [Male herbalist, 70 years old; Interviewed 03.03.2014]

Historical and biomedical knowledge shaped these understandings of the disease. Another elder (BMU member, discussion on 11.03.14) wondered if *Buruli* was acquired from the tools used by fishermen in the past, such as the hooks and nails.

For others, they drew on visible experiences. A number associated it with eating mudfish⁹¹. When they are gutting the fish, they sometimes see small white worms in the stomach or gills, and they suspect that these worms might be the cause of *Buruli*. In addition, when the wound of *Buruli* was cut open by the herbalist, they described small white eggs that were removed from the wound.

Many did not know how it was caused or transmitted. One herbalist said: '*Perhaps it comes from God, because otherwise I don't know*' [Male herbalist, born 1920's; Interviewed 06.02.2014], showing an inability to explain the cause. Despite this inability to explain it, by and large, people did not associate *Buruli* with forms of witchcraft or local poisoning (as is more often the case described in literature from West Africa, for example Stienstra et al, 2002).

Typically, local poison was either put in somebody's food and ingested, or, as is the case with *erua hwe* ('tree medicine') placed on the ground affecting somebody who walks over it. Poisoning is purposefully afflicted by someone, although not necessarily directed to one particular person, as is often the case with *erua hwe*. For *Buruli*, local herbalists were clear that it could not be inflicted on you by another person. Although it was often stated following this that you should be very careful with how you manage the waste from cleaning the wound, as one herbalist pointed out, 'so that no one can tamper with it'.

Even earlier in the twentieth century, when some of the herbalists were training, they denied that these lesions had ever been a form of witchcraft or local poisoning. Although a woman, who was 62 years old and had suffered *Buruli* when 20 years old, reflected:

⁹¹Not from going to catch mudfish. Mudfish is sometimes caught in the River Nile, but also caught in other rivers in the rainy season that feed into the Nile. The men catch them with spears as the fish swim down these muddy rivers.

Before [during the 1960's] people would think it was erua hwe or inyinya (forms of local poisoning) and they were using drugs of those ones but they were not getting it [it was not healing]. And then they realised it was not these two [forms of poisoning] and started to find other treatments.

[Interviewed 04.03.14]

People's explanations therefore, did differ. By and large these ulcers were not understood as a form of local poisoning, and for the majority of people the symptoms of the two afflictions were quite different. As a herbalist reported:

With poison, it will not cause a wound. It goes into the blood vessels and destroys the organs. [Elder, local herbalist, 70 years old, interviewed 03.03.14]

Another man, aged 52 years old, who had suffered *Buruli* when he was 14 years old, reported that he had not seen late ulcer. When asked about local poisoning and *erua hwe*, replied:

The one of erua hwe or others is quite different. It doesn't bring wounds like this, but pain [interviewed 04.03.14].

This is how the majority of people explained local poisoning, but the distinction between *Buruli* and witchcraft was not clear cut both in people's reflections on the past, as previously demonstrated, and also currently. For instance, late ulcer, where the skin has been destroyed exposing underlying tissue, for the majority of people was sometimes identified as *Buruli*. For those who had not seen it, they did not

have an explanation. Yet a minority⁹² reported that late ulcer can be caused by '*erua hwe*'.

When shown the poster of Buruli lesions, one herbalist said of the late ulcer picture:

This is that which has been reported late and the person treating is fearful and hasn't done a good cut. That one [late ulcer] is not really Buruli, if it is realised, if it is really late Buruli it will eat your flesh and bones. But here, where you see the flesh alone is taken away, that is caused by erua hwe.

[Elder, local herbalist, 70 years old, interviewed 03.03.14]

This herbalist went on to say that he had seen a case of late ulcer as shown on the Buruli Ulcer poster recently.

Last month, a certain woman died of such erua hwe after stepping on it. When you wash the leg, the flesh falls off and only the bones are left. She died in hospital. You can't cut it, only wash it, and as you wash, the flesh falls off. She also arrived late [to seek treatment]. [Elder, local herbalist;

interviewed 03.03.2014]

This last point about arriving late for healthcare was a concern for all treatment providers, whether herbalists or biomedical practitioners and whether for ulcers or forms of local poisoning. This will be discussed further on in the chapter. What these quotes also demonstrate is that for *Buruli*, the wound that 'heals in vain' and 'eats the flesh from the inside', the severe, late stages of the ulcers were explained by some people as *erua hwe*. Alongside this, there were many uncertainties surrounding disease transmission and the limited effective biomedical treatment available. Therefore, it is not surprising that these cases were explained as an

⁹² Three responses.

affliction from local poisoning. It may be that particular types of ulcer are ascribed as relating to local poisoning, whereas others are categorised as *Buruli*. When asked if he had ever had *Buruli*, one elder responded:

He points to his left leg, lower leg above the ankle where a wound has healed. It was not Buruli; but he was poisoned, he explains. He describes a game that children used to play (the research assistant agrees, they also used to play it as a game). You put clay on top of a stick and throw it. They called it 'lacu ruka'. But here, it was not a game. They would put local poison on the clay and then hit you from afar. Neither of them are sure where the poison comes from or what is used.

"I stayed down for two years with the wound. It was like that of Buruli, but was not Buruli. Local herbs were also applied to treat it. These herbs were anti-poison, which you apply on the wound and also drink. Then you pass the poison that has reached inside out with diarrhoea. The herbalist uses different herbs to that of Buruli.

The one of Buruli, it collects and is cut. But this one, the whole leg itches and you can get paralysed. I know the difference between the two (Buruli and this poison), because the son of my brother had Buruli. This one, the poison, is only cut superficially, not deep.

I was 18 years old when I had this. When it happens, you don't know who has hit you. Those who throw say, 'a dove has been caught'. They are hitting anybody who passes; not targeting specific people. Some people die if no local herbs are applied. It was both my parents who took me to my maternal uncle who knows the herbs. You don't find out who did it. The herbalist demands payment, in cash or kind (such as goats). The herbalist came to

stay with us, to monitor. And he washed the wound and applied herbs. He stayed for one full month and thereafter came to check on me from his home.” [Male elder fisher and farmer, interviewed 03.02.2014]

Again it was a severe form of ulcer that was identified as poison. Despite these accounts, these ulcers were predominantly understood as *Buruli*, and drew on biomedical understandings of worms and germs. Yet as we have begun to see, the mainstay treatment for ulcers, *jue* and *Buruli* is from the local herbalist. The man’s account above of his ulcer was differentiated from *Buruli* on a number of accounts: first by the symptoms, and second by the treatment.

BURULI SYMPTOMS

The majority of people recalled quite clearly their experiences of *Buruli*. Some were affected only once, others multiple times. The majority were affected on their legs⁹³. Their descriptions fit the clinical picture of Buruli ulcer. Most commonly, people reported that it started with an itch, like a small prick of a thorn⁹⁴, or with a swelling (like oedema)⁹⁵. Others first noticed a small nodule⁹⁶, and a minority experienced pain⁹⁷ or pins and needles⁹⁸. The most common description was that it had started with an itching that developed within a few days into a small swelling or overlying skin changes.

A 20 year old female fishmonger described her experience of *Buruli* when she was eight years old:

⁹³ Overall 29 episodes of Buruli ulcer were discussed. Of these, 22 were on the lower limb, three on the upper limb, two on the breast, two on the head and neck, and none on the trunk.

⁹⁴ Twelve responses.

⁹⁵ Eleven responses.

⁹⁶ Four responses.

⁹⁷ Three responses.

⁹⁸ One response.

"It started when I was going to fetch water. As I was walking, I felt at the buttocks itching, and started scratching. On the second day it started swelling." [Interviewed 04.02.2014]

Another recalled:

"I suffered from Buruli in 2002, on my right leg. I first had that feeling as if I had sat on one leg for a long time. This was there for one or two days. Thereafter, the leg was paining and swelling [on the right thigh]. People around said it might be a boil. They took me to a herbalist who said it was Buruli, but he couldn't treat Buruli so I was taken to another herbalist..."
[Female fishmonger, 28 years old; interviewed 04.02.2014]

This woman described the sensations (pins and needles) in a different way to most. More typically people's experiences were similar to this fisherman's description:

I was in Primary school, in 1994, when I got this attack of Buruli ulcer on my right knee (he shows the scar of the ulcer and of the cutting by the local herbalist). I was coming from school and got an itching as if something had bitten me on the knee. I was itching and scratching the spot and it became lighter. This carried on for four days, and it was experts [herbalists] at home who examined me. They touched it and said it was Buruli. [Male fisher, 36 years old; interviewed 28.01.2014]

These descriptions, like many others, show not only the initial symptoms but also how within a few days, people sought 'expert' advice. Contrary to how the presentation of Buruli ulcer is seen at the health centre, where people are perceived to present late when the ulcer has developed, the majority of people sought what was deemed appropriate healthcare relatively quickly. When people

were affected by symptoms of *Buruli*, they were advised by parents or other family members on where to seek treatment. For the vast majority of people this was to a local herbalist and in most cases, people went to the herbalist within a few days of experiencing symptoms.

The herbalist, often called an '*expert*', tended to be either a relative (generally male and often a maternal uncle, grandfather or father) or somebody from the village who was known to treat *Buruli*. Their use of the translated word '*expert*' demonstrates the high regard for and trust in the herbalist and their treatment, and also the perceived efficacy of their treatment. As already seen, the longevity of the disease and the local management of *Buruli* are influential, but what else is it about the herbalist and his treatment that has developed this status?

HERBALIST'S TREATMENT

The herbalists who treated *Buruli* and *jue* learnt their skills, techniques and the herbs to be used from another herbalist. Their teacher was an elder at the time that they were growing up and often a relative. They spent time with this elder, months, even years, and he passed on his knowledge to them as the next generation of healers. Sometimes, they reported, their knowledge to have been originally acquired through dreams. Sometimes, they reported, they used trial and error to find the right herbs to use. The herbs themselves tended to be found growing wild around the home. One herbalist, almost laughing pointed to the common grasses around his house that he used, and said, 'you see, these people don't know'. But some herbalists travelled further to collect them, often at the foot of a mountain.

Local herbs are referred to as *erua Madi* in Madi (literally, 'Madi medicine'), or *erua abi dri* more generally for non-Madi's (*abi* meaning grandfather or ancestors, *dri*

meaning hand, therefore 'medicine from ancestors', or 'medicine given by ancestors'). This is opposed to *erua Mundro* ('White's medicine', effectively biomedicine).

When someone attended them with *jue* or *Buruli*, the herbalist first assessed whether the lesion was *Buruli*, boil or another condition. One herbalist described examining for what would biomedically be termed 'pitting oedema'. He tested by pressing the swelling and if it left an indentation, this was a sign of *Buruli*. Another test for determining *Buruli* was to cut at the site of the lesion (for example on the leg) and cut somewhere else (for example on the arm), demonstrating to the patient that the colour of the blood from the area with *Buruli* was darker than the colour of blood from elsewhere. Both these tests were visible signs for the herbalist and, as particularly described in the latter case, for the patient.

The treatment given by a herbalist varied to a certain degree, but the general approach was the same. One male fisher quoted before went on to say:

It was four days from when the itching started to when the whole area became brown and paining inside. There was no swelling. As I kept scratching, the colour of the skin became light.

Within these four days, I immediately went to the expert. Straight away the herbalist cut me with a razor blade small, small [superficially] and applied local herbs. On day six, the herbalist said it was now ready to be cut deep and pus came out. Day six he cut three deep holes; day seven he checked it; day nine he cut four more deep cuts. He continued like this up [to the thigh] and down [the shin]. The pus was coming from the wound on the knee, not the cuts to the leg. The cuts were made higher up so that the germ didn't spread further.

It took one year and four months before I could walk. The wound almost took out my knee cap; it almost became stiff but because I was brave I kept moving the leg. [Male fisher, 36 years old; interviewed 28.01.2014]

As described here, the herbalist began by making small superficial cuts to the skin around where the problem was, *'to make the 'germs' collect in one place'*. Often, it was reported, if after three days the swelling had collected into one place the herbalist made a deep cut over the swelling to release pus. Further deep cuts were made immediately around the swelling. From the first day the herbalist would apply a mixture of local herbs. One herbalist described how he applied fresh herbs on the first day. On subsequent days he applied these same herbs that he had dried and pounded into a powder. Different herbalists used different herbs, either roots or leaves of various plants, depending on what they had been taught. In addition to the herbs that were applied topically over the wound, some herbalists also made a drink from the herbs. Although others only applied topical herbs for *Buruli*; a herbal drink being used for local poisoning as local poisoning was something that went inside the body, into the blood. In these cases, the herbs bring on diarrhoea which expels the poison.

The treatment described was sometimes quite extensive, especially considering there would be no anaesthetic, with the wounds taking months to heal. One woman described her experience of the treatment:

... when I got it, it was so bad. I was nearly dying from the smell of the wound on my knee. My father said that they needed to treat it seriously, but that it would be so painful that I must be held down. But I explained that I didn't need holding down, as I was nearly dying. [Discussion with female fishmongers, 28.02.14]

As this woman's description illustrates, the severity of the ulcer and the treatment can be extreme. One herbalist explained to me that in the past, when severe forms of the disease were more commonly seen, to identify the edge of the infection the herbalists made a cut and pushed a small, smooth stick into the wound parallel to and just under the skin. At this place, the next cut was made and the process was repeated until the wound had been cleared of pus. These deep cuts were made and completed in one sitting. Demonstrating the expertise of the herbalist, one explained, '*You cannot be fearful to cut*' [Elder, local herbalist, 70 years old, interviewed 03.03.14]. He went on to explain that if the cutting is not completed in one sitting, '*it will continue to eat the flesh*' and the wound will spread, developing into a late ulcer which was more difficult to treat.

There were other long-term effects for those who had experienced *Buruli*. Some forms of Buruli ulcer heal spontaneously, but more advanced lesions can take much longer. Among those we spoke to who had experienced *Buruli*, the wounds took weeks⁹⁹, months¹⁰⁰ or years¹⁰¹ to heal. There were reports of people having died from late ulcer lesions, but most people it seemed recovered and healed with little long-term sequelae except scarring, which people openly showed when the topic of *Buruli* came up. Some of these scars were the depressed scars of the ulcer itself, but many scars were from the herbalist's cuts. Sometimes these cuts extended along the length of the limb. For a few people¹⁰², *Buruli* had affected the use of the limb and one woman who had had *Buruli* on her breast subsequently had difficulties with breastfeeding. It was common for people to suffer from pain long after the ulcers had healed. In particular, people experienced pain at the time it

⁹⁹ Three cases.

¹⁰⁰ Eleven cases.

¹⁰¹ Two cases, plus one case of local poisoning.

¹⁰² Three cases.

rains. One male elder continued to make superficial cuts and apply herbs to his leg each year when the rainy season began and his pain returned.

For a number of people their nodules, swellings and ulcers healed¹⁰³. Even though in the few more severe cases the herbalist's treatment may fail, it was also in these cases that biomedical treatment often failed. Therefore, rather than undermining the herbalist's efficacy, it arguably reinforces his expertise, both practitioners struggling to manage a difficult case. While I have mainly discussed the management of *Buruli* by herbalists, the relationship between both forms of healthcare is significant, and arguably it is becoming more so. The use of biomedicine has not undermined local herbalist's medicines. As we will see, biomedicine has not become the dominant form of healthcare as is the case for bilharzia, with herbalists still seen as the primary healthcare provider for ulcers and nodules.

LOCAL HERBALISTS AND BIOMEDICINE

For people living and working along the River Nile their understandings of *Buruli* drew on both local and biomedical knowledge and practice but predominantly, the treatment sought was from a local herbalist. Within this, both biomedical and herbalist treatment were used, which appeared to be especially the case more recently. Some people who had experienced *Buruli* solely received treatment from the local herbalist. There was only one exception: a male fisher (23 years old), [interviewed on 03.02.2014] who was taken by his parents to a nearby health centre

¹⁰³ This is also not to say that *Buruli* ulcer has not had serious consequences for those who have been affected. *Buruli* had also affected some people's day to day lives. Mainly this was being unable to carry out the household chores expected of them, such as washing clothes at the river, or cooking and cleaning around the homestead. Three people had dropped out of school when they developed *Buruli*. One returned a year later; but the other two did not. One had had severe ulcerative disease which kept them away from school; and the other subsequently fled into exile in Sudan with his family and during this time did not return to school.

and only received biomedical treatment. However others, especially those who had been affected in the last fifteen years, reported that they initially went to a local herbalist for the affected area to be cut, and following this they went to a health centre for antibiotic injections.

For instance, a 30 year old woman [interviewed 11.03.14] first received treatment from a local herbalist. She then concurrently received injections from a local health centre, before later being admitted to the district hospital where her leg was amputated. Another man [interviewed 14.03.14] had suffered from *Buruli* three times in the 1980's and 1990's. The first time, he solely treated it with local herbs. However, when the ulcer re-occurred a second time he concluded that the local herbs had not fully treated it and so he went to a health centre for biomedical treatment. The third time it recurred, during which time he was displaced due to conflict in the 1990's, he went back to using local herbs. For *Buruli* then both herbalist medicine and biomedicine *can* be used, although predominantly the herbalist's medicine was used.

This needs to be understood alongside the contrasting situations where only local medicine was used and biomedicine *can't* be used. This was the case for local poisoning. Cases of local poisoning were understood through interpersonal explanations, as sicknesses caused by the deliberate actions of others out of jealousy or by people wanting to cause suffering. For the Madi, sicknesses that are due to local poisoning or witchcraft are in part distinguished by their treatment. For local poisoning, the treatment is *erua Madi*¹⁰⁴. If someone is affected by local poisoning and consumes *erua Mundro* their condition deteriorates, they experience a bad reaction to the medicine which can be fatal. During an interview about *Buruli*,

¹⁰⁴ For simplicity, I will just refer to *erua Madi*, but the same holds true for other local medicine among non-Madi i.e. *erua abi dri* more generally.

one female fishmonger described a separate experience of local poisoning that was initially treated at the hospital:

There was another serious sickness I had when I stepped on something [erua hwe] that pricked me. I was more than fifteen years old. I reported it to my parents as it was paining me. After three days it got worse and so they took me to Adjumani hospital. I had my stool examined and was given drugs from the hospital. Our people say that if you take erua Mundro for local poisoning, it will increase. So it got worse ... Within three days I experienced my head turning [in painful spasm]. When I stopped the hospital medicine and begun the local herbs, it resolved ... So they took me to a local herbalist and I was treated for four months. They were cutting and applying local herbs, and I was taking a drink of herbs. This drink gave me lots of diarrhoea. There was no big wound to treat – only the pain. [Female fishmonger, 20 years old; interviewed 04.02.2014]

This woman could well have experienced an adverse reaction to the biomedicine administered in the hospital. The experience however, was understood to be a sign that not only was it a reaction to biomedicine but that therefore it was not a biomedical cause of her initial problem. Rather it was a local cause, a form of poisoning. This was reinforced by the fact that when the biomedicine was stopped and the herbalist's treatment started, the reaction subsided. Herbalists are therefore deemed best placed to deal with particular conditions.

As demonstrated, local herbs were also used for *Buruli*, but in contrast to local poisoning, this was not because it was thought of as a local disease due to its causality. In fact, its causality was overwhelmingly thought of in biomedical terms. Not only have these swellings and ulcers taken on the common biomedical name of

Buruli in Madi, but the disease was understood within a biomedical framework, drawing on understandings of worms and germs. Yet *Buruli* was a local, or Madi, disease in terms of its treatment. Local herbs remain the primary, or at least initial, treatment for those living along the River Nile.

It may well be, as one woman alluded to, that explanations have changed over time. Perhaps with the increase in biomedical healthcare available and the suppression of notions of sorcery and ancestral beliefs by the Catholic Church (in Allen and Storm, 2012), biomedical explanations have become more prominent. There appears however to have been little change in this for *Buruli* over the last 30 years.

From long-term fieldwork in the 1980's, Allen (1992, p.235-236) describes a similar situation in the treatment of *Buruli*. *Buruli* was believed to be a Madi illness, although from impersonal causes, requiring local treatment from herbalists. This was reinforced by the fact that standard antibiotics did not effectively treat the disease. As reported by one local herbalist (quoted previously), with ineffective biomedicine, it was thought that the biomedical healthcare workers did not know how to treat these ulcers, thereby undermining the use of biomedicine and further supporting the use of local herbalists. Allen notes that while some people suffered severe consequences from the herbalist's treatment (secondary infections and even fatalities), others survived and were cured. Despite the fact that there were some cases of severe complications and fatalities, some cases of severe disease were cured which further promoted the herbalist's treatment.

Even further back we see it was likely to be a similar picture. Lunn et al's (1965) study of *Buruli* ulcer in Madi District in the 1960's found that out of 39 new cases of *Buruli* ulcer disease, "On two occasions patients were found to be applying powdered herbs, a procedure which forms a thick dry crust over the ulcer bed"

(ibid. p.278). It is surprising that they observed the use of herbs for treatment on only two occasions. The authors also reported evidence of 'burnt-out' cases: "some parents displayed their children proudly, affirming that their ulcers had healed without Western medicine" (ibid. p.279).

Local treatment is still the predominant approach, and the fact that there has not been a dramatic change in treatment is not surprising. This is in part because of the perceived efficacy of local herbalist treatment. There may be biomedical explanations for this. It has been reported that one third of early stage Buruli nodules resolve spontaneously and excision can cure early nodules (84% cure rate) (Wansborough-Jones and Philips, 2006). In addition, in Ghana, antimicrobial properties have been identified in the herbs used and the hot poultices applied (Addo et al, 2008 cited in Ackumey et al, 2011). It may well be that aspects of the herbalist's treatment are effectively treating the lesions.

Yet people's response to managing *Buruli* is arguably not only because of the perceived efficacy of local treatment, but also a perceived lack of efficacy of biomedical treatment. There has not been a concerted public health strategy to actively identify and treat cases of Buruli ulcer. In fact, from what I could ascertain, the antibiotics given at the local health centre for Buruli ulcer were not the recommended tuberculosis antibiotics, but broad spectrum antibiotics that would nonetheless treat other bacterial infections. As we saw with schistosomiasis, there is now much demand for biomedical treatment, which in part has been driven by a perceived benefit of biomedicine (through mass drug administration) over a decade. This is not the case for *Buruli*, therefore it is not surprising that there hasn't been an overwhelming shift towards a biomedical approach to treatment.

This does not mean that biomedicine has had no influence. It has arguably had an influence on the herbalists' practice. This is perhaps in part from the attempts to 'professionalise herbalists' (Allen, 1992). There was a herbalist association in Adjumani town, but while some herbalists worked side by side, the majority still practiced independently at their home. Herbalists have however incorporated aspects of biomedical healthcare into their practice. This was seen in one herbalist's detailed biomedical knowledge of the disease (Buruli being caused by bacteria). This herbalist, who was treating a number of people at his home at the time, showed me his consultation record book with details on the patient, sickness, and treatment given. It was much like a hospital record book.

It was also seen in the use of razor blades for cutting and in waste disposal management. Before people went into exile in the Sudan in the 1980's, herbalists made the cuts using the head of a spear made locally from iron [Elder, local herbalist, 70 years old, interviewed 03.03.14]. This practice changed when razor blades became available. It was reported that patients are now required to bring their own razor blades. The razor blade is then only used for one person, as a herbalist explained, '*You see, you can't use the blade on this person, and then that one: you can't pass on AIDS*' [Male herbalist, 56 years old; interviewed 07.02.2014]. Local herbalists used the knowledge passed on to them, but they also incorporated biomedical knowledge, adapted to new developments and to other biomedical threats such as HIV.

In addition, when a herbalist was treating a patient with *Buruli*, he dug a hole in the ground and supporting the limb over it, washed the pus from the wound and water into the hole which was then filled in. The herbalist informed people not to disturb the places where the waste water and pus had been buried. Reflecting on the fact that in the past they saw more cases of *Buruli* and within a homestead there could

be a number of people affected, he postulated that perhaps this method of burying waste was not carried out. Both the symptoms of *Buruli* and its management by local herbalists were visible and based on empirical observations that have informed practice over time.

People's management of *Buruli* has also adapted to the availability of biomedicine. While herbalists are the primary healthcare providers for *Buruli*, both forms of treatment are an option. While this appears to be more common now, this has not been without tensions between the herbalists and health centre personnel. As one herbalist recalled:

Three years ago I was treating someone here and a nurse came around and started quarrelling. She was quarrelling that I should not be treating these things and she said that she should take me to the authorities. But I said, 'you take me, for if this person comes to you, you will wait and wait saying it is not ready yet, whilst inside it is rotting.' Now later she came back and apologized, that they are meant to say these things. Now she advised me to do the cutting and then when it is finished with the cutting and just a wound, then I should send them to the health centre for antibiotics (he mimes sprinkling antibiotics on the wound, possibly tetracycline), 'PPF'¹⁰⁵, and dressing. [Interview with elder, male herbalist, 70 years old; 03.03.2014]

Both forms of antibiotics (topical and injected) were seen as what biomedicine had to offer for *Buruli* ulcer. But, as this herbalist explains, for *Buruli* it is the cutting and

¹⁰⁵A penicillin based antibiotic (Procaine Penicillin Forte), referred to by many in its abbreviated form, PPF.

visible release of pus that is important. Otherwise neither treatment will work. This is a key part of the herbalists' treatment, not just the herbs applied.

Some studies on Buruli ulcer have suggested that a fear of surgery (Stienstra et al 2002), of extensive excision of the ulcer and amputation, leads people to avoid hospital care and seek traditional healers (e.g. Debacker et al 2004a). However, in Moyo and Adjumani, this does not appear to be the case. In fact, the herbalist's treatment was sometimes extensive. Indeed, in some instances, treatment by the local herbalist was preferred because of a perceived *lack* of intervention by medical staff at the health centre. In one village, women described how the health centre 'feared' to cut a boil and referred patients to a herbalist for cutting, although the herbalist denied knowing about this. In other cases of *Buruli*, as the herbalist above also said, people described how the condition would get worse if somebody attended the health centre as the medical staff would wait before lancing the nodule, or they did not make cuts at all and only gave antibiotic injections.

On the other hand, one concern from medical staff about the use of local herbs for these conditions is that people then present for treatment in later stages of disease when complications have arisen and the management is more difficult. This was also a concern for herbalists for the same reasons. One herbalist remarked that in the past people would come to them too late for treatment, but now people are aware that if you go to the herbalist early, you can be cured within a few days and without the need for deep cuts. In this respect, rather than ignoring initial symptoms for *Buruli* and *jue*, people were responding quickly to their symptoms and seeking out treatment that was deemed appropriate (whether solely from the herbalist or a combination of local and biomedical treatment), even if that doesn't fit biomedical notions of appropriate treatment.

While the health centre still predominantly sees the late stage ulcers that are difficult to manage, one herbalist remarked that these cases were in fact reducing. It was now rare to find people who had severe lesions with extensive tissue destruction:

[Buruli] is practically getting finished; they might get rid of it one day. Because these days it rarely goes to deep cuts, only the small cuts. It has changed because you hardly can now get the big cuts. It is only the adults now, who were treated a long time ago. [Elder, male herbalist, 70 years old; interviewed 03.03.2014]

From this herbalist's observations, the severity of Buruli ulcer was reducing. However, cases of severe ulcer were still seen (including a young woman treated in 2013 who had her leg amputated) and cases of ulcers explained as *erua hwe* (as described earlier by one of the herbalists). Occurring outside the health centre, these patterns of disease over time were largely not visible to biomedical healthcare. There wasn't reliable biomedical data on prevalence of Buruli ulcer to determine if the prevalence of disease has decreased over time. However, a district staff member also reported that Buruli ulcer is 'near eradication'. It is not clear if or how this has come about.

In terms of the distribution of Buruli ulcer, people were still involved in fishing and digging along areas near the river where the disease is likely to be found. It has in fact been speculated that there may be an association between Buruli ulcer and schistosomiasis and other intestinal helminths through immune-mediated pathways (Stienstra et al, 2001) (which would draw interesting parallels with the low levels of schistosomiasis and helminth infections found in the parasitological survey).

However, this association has not been confirmed in a case-control design study (Stienstra et al, 2004).

Whatever the reality of the epidemiological patterns of disease in the districts, *Buruli* is still significant along the river in Moyo and Adjumani, but perhaps not in the way that it is portrayed by the terms used in global health narratives. There is a wealth of knowledge surrounding *Buruli* that has been passed down over generations and developed over time, incorporating both local and biomedical knowledge. This is seen with the herbalists, whose skills and techniques have been learnt and developed over time. It is also seen with biomedical treatment, such as the use of antibiotics, which has been adopted alongside herbalist treatment.

While we cannot say for certain that all the cases discussed as *Buruli* were in fact Buruli ulcer (although they do largely fit the biomedical picture), what is important is people's perceptions of a disease (as, for example, Hausmann-Muela et al's work on malaria, 2002). Previous experiences shape current responses to *Buruli* and boils. When asked how they would advise others, invariably the answer would be to go to the herbalist. Not only because this treatment had worked for them, but because treatment from the health centre was deemed insufficient alone.

Sometimes people weren't aware of biomedical treatment, as one woman asked: '*but is there treatment at the health centre?*' Biomedical treatment for Buruli ulcer has largely not been endorsed by people as an initial or sole treatment for *Buruli*, probably because the antibiotics commonly used are relatively ineffective.

Additionally, frequently there is limited drug stock at the health centres with biomedicines unavailable, which further undermines biomedicine as a credible source of treatment.

The situation is likely to be different in the towns, where there is access to the hospital clinic and many private clinics. In Adjumani, when a young boy developed 'jue' his mother took him without question to a nearby private clinic for lancing and antibiotics. However, at a landing site, a young fisherman who developed a painful swelling on his leg adamantly refused to attend the health centre for treatment, even with an offer of a lift. "This is just jue; I will deal with it, I will cut it tonight at home". He lanced the swelling with the end of a feather, releasing pus to demonstrate that it is 'just jue'. Others around confirmed, *jue* was treated at home not at the health centre.

Along the river, *buruli*, like *jue*, was overwhelmingly treated at home by local herbalists. People trusted the herbalist as the expert, and while now they might use biomedicine alongside a herbalist's treatment, this is not for a perceived lack of efficacy of the herbalist's treatment, but a merging of the use of both forms of therapy¹⁰⁶. Even a woman who had recently had her leg amputated above the knee because of Buruli ulcer did not question the disease or the treatment. She had initially received treatment from a local herbalist, and subsequently from both the herbalist and the health centre. The main concerns for her were on how she might access a wheelchair and an artificial limb. More pressingly for the healthcare worker, he was concerned with obtaining the correct crepe bandages to protect the stump of the leg. These needs were what concerned people more significantly in relation to their health: the constraints and limitations of the biomedical healthcare system.

BURULI ULCER: AN EMERGING PUBLIC HEALTH CONCERN FOR WHOM?

¹⁰⁶ The term *medical syncretism*, as opposed to medical pluralism, has been developed to describe the merging of traditional and biomedical concepts (Hausmann-Muela et al 2002).

Buruli ulcer received global health attention from 1997 following a visit by the director general of the WHO to West Africa where the disease is highly endemic. It was said to be an 'emerging public health concern', and framed within the group of neglected tropical diseases. Yet for those living and working along the River Nile in Moyo and Adjumani, an area historically endemic for Buruli ulcer, it was a well-known affliction with many words to describe the ulcer long before the introduction of biomedicine and the term 'Buruli'. For those vulnerable to infection and those that have been affected it is neither emerging nor seen as a particular threat.

Buruli was understood to respond to local treatment and to be largely beyond the capacity of biomedical treatment. These understandings of nodules and ulcers and their treatment are drawn from generations of experience that these skin diseases are treated by local healers with cutting and the application of local herbs. The fact that many nodules and ulcers do heal provides empirical proof of the capacity of local healers. Therefore, the management by health centres, which often initially involves broad-spectrum antibiotics without lancing the nodule, is perceived as insufficient. Past experiences have demonstrated to people that biomedical treatment does not work. In addition, current experiences of healthcare services reinforce this. With limited drug stock and understaffing there is little incentive to seek treatment from the health centre. People have their own management strategies, and from their perspective there is little need to question a lack of biomedical input or even seek it, at least initially.

Within this context and given people's perceptions and experiences, this healthcare choice is deemed appropriate and rational. This is not to say that no biomedical treatment has been adopted. More recently, antibiotics are sought alongside a herbalist's treatment. However for a majority, biomedicine alone is not deemed effective management. Understandings of Buruli are largely based on biomedical

knowledge and frameworks, and this has also been incorporated into the herbalists' management. Throughout though, the herbalist has remained the primary healthcare provider, at least initially.

The intent is not to reify local medicine or biomedicine, but to illustrate the situation as it was found. Whatever the biomedical cause of these ulcers and nodules, people understood them as *Buruli, jue* or poisoning. The treatment for each was from a herbalist. Even if some of these lesions now are not Buruli ulcer, peoples' past experiences have shaped their current responses. These have been shaped by the efficacy of the herbalist treatment and the inefficacy of biomedicine alone. Whether for Buruli or other ulcers, boils and nodules, the local herbalist is seen as the expert and their status has been reinforced.

The importance of this for biomedicine is that for health staff, Buruli ulcer relies on the self-presentation of sufferers to the hospital, yet, in the context described in this chapter, people rarely do so. As the doctor quoted at the beginning said, '*What do you know about Buruli ulcer?*' It was a disease that occurred deep in the village, but rarely confronted in the hospitals. What is advised by global health initiatives is not necessarily feasible for the district with scarce resources within the national health system. In Moyo and Adjumani districts, there has not been a vertical programme for Buruli ulcer and no active case finding (as has previously been the case with sleeping sickness). As a district vector control officer, knowledgeable about Buruli ulcer, said:

"Buruli is under NTD and I have seen the posters around; but I am not sure if there is a particular health programme for it", and when shown the poster, he remarked: "It is from the Global Buruli Ulcer Initiative, World Health

Organisation. You see, it is still under the WHO; not a local organisation.”

[Discussion 30.01.14]

There has been little translation from global health advocacy to local management. Part of this is that it is rarely seen in the health centres, it being largely managed as a local disease requiring local treatment.

From a global health perspective, Buruli ulcer is ‘an emerging disease of public health concern’. Yet it was first described and identified over a century ago, and it was a concern for medical doctors during the twentieth century alongside other forms of skin disease and ulcers (Vaughan, 1991). But Buruli ulcer has been re-introduced as a public health concern by engaging in it internationally as a neglected tropical disease. For the district staff, it is a neglected disease in many senses of the term. It is a disease affecting a ‘hard to reach’ population, with no local public health strategy and limited medical treatment available through the public health system.

From the perspective of those who have suffered from it and managed it though, it is a continuing (although perhaps reducing) problem of *jue*, *Buruli*, ulcers and local poisoning that have long been treated by local herbalists. The framing of Buruli ulcer as an emerging disease does not reflect how it is perceived by the people who are afflicted in Moyo and Adjumani districts. While neglected from public health policy, people along the river had developed understandings and strategies to manage the associated illnesses. The situation is strikingly different for hepatitis B, the disease discussed in the following chapter.

6. HEPATITIS B: A 'SILENT EPIDEMIC'

While visiting the district hospital in Adjumani over the first two months of living there, it became clear that on the medical ward a number of patients, predominantly males but also some females, were being admitted with hepatitis B. After a blood test confirming the presence of infection, with no facility in the district to perform liver function blood tests and no working ultrasound machine in the hospital, patients were sent to a private clinic for an ultrasound scan. In addition to liver damage from the hepatitis B virus (inflammation and cirrhosis of the liver itself), some scan reports showed signs that were consistent with schistosomiasis (periportal fibrosis and portal hypertension, affecting the portal vein of the liver). A 'double insult to the liver', a doctor explained to me, or a triple insult if alcohol related liver damage was added. It became clear that the outcomes of patients admitted with liver disease were poor. Men in particular were dying on the hospital ward from liver complications and hepatitis B.

I didn't pursue this line of enquiry much further until after the parasitological survey. But both before and after the survey, the topic of hepatitis came up when discussing with men and women at the landing sites. Often unprompted, somebody would say '*but what about hepatitis?*', '*what about liver disease? That is really affecting people these days*', '*this disease, that followed AIDS*'. People were eager to talk about this 'new disease', to make sense of the uncertainties that it had brought.

In contrast to Buruli ulcer, hepatitis B as a disease does not have a long-known history among people, although the symptoms had previously been thought of as other illnesses. Therefore, how have people made sense of this new disease?

What shapes this response, and how does it shape people's responses to healthcare? What does this mean for a discussion on neglected tropical diseases?

This chapter answers these questions by drawing on discussions, observations and data provided by the districts and private clinics. It begins by providing an overview of the epidemiology of hepatitis B and its management. It is not an epidemiological study of hepatitis in the districts¹⁰⁷. Instead, it discusses the social responses to this emerging disease, how it has presented itself to people living and working along the River Nile in Moyo and Adjumani Districts. This chapter has two main points. Firstly, it looks at how people have understood the emerging disease. While sometimes understandings of witchcraft were drawn upon, more overwhelmingly it was understood within people's experiences of HIV/AIDS¹⁰⁸. These experiences have shaped people's responses to the disease and perceptions of healthcare provided. Finally, the chapter discusses the constraints faced by the public health system in the districts for managing the disease. In doing so it concludes by questioning how this known global public health concern was able to become a 'silent epidemic', and to emerge as a new disease. Hepatitis has arguably been neglected, which calls into question the misleading notion of 'neglected tropical diseases'.

EPIDEMIOLOGY AND PUBLIC HEALTH MANAGEMENT OF HEPATITIS

¹⁰⁷ It was not feasible during this fieldwork to conduct epidemiological studies on all the diseases discussed, including hepatitis B. This would require additional research. I therefore draw on available data, while acknowledging that this is incomplete.

¹⁰⁸ This is situated within Susan Whyte's ethnographic research (1997) on afflictions and misfortune in eastern Uganda. She emphasises a pragmatic approach in understanding people's exploration of uncertainty and suffering. With the emergence of HIV/AIDS and the proliferation of biomedicine, this had not always lived up to its expectations of treatment, which is also understood within the pragmatics of uncertainty.

The term hepatitis describes inflammation of the liver. This is commonly caused by alcohol or viruses. There are five types of known hepatitis virus, A to E, that are either passed by faecal-oral transmission (types A and E) or via infected blood or other body fluids (types B, C and D). This chapter is concerned with hepatitis B, which causes both acute and chronic liver disease¹⁰⁹. Globally, more than 240 million people have chronic liver infection; and more than 780, 000 people die each year due to acute or chronic disease (WHO¹¹⁰). It affects people worldwide, predominantly in Africa and East Asia (ibid.).

Viral hepatitis has been described in a WHO report as a “silent epidemic” due to the asymptomatic nature of the disease among many individuals’ infected (WHO 2013 p.1). Only a third of adults have symptoms of acute hepatitis (flu-like symptoms, nausea, vomiting, diarrhoea, loss of appetite, jaundice), with the majority experiencing subclinical disease (Hoofnagle et al 2007, p.1058). Some people become chronic carriers of infection¹¹¹ and can therefore continue to transmit the virus to others while not being acutely unwell themselves. Chronic hepatitis B infection can lead to irreversible liver damage, cirrhosis and liver cancer (e.g. Lok 2000 p.93). The risk of developing cirrhosis and liver cancer¹¹² is higher if infected at birth or in childhood (Fattovitch, Bortolotti & Donato 2008) which will have implications in areas where perinatal or childhood transmission is high.

¹⁰⁹ Disease patterns can vary, between acute, transient infections (where there is not a complete eradication of the virus, but immunological control (see Hoofnagle et al 2007) which can lead to the risk of reactivation of the disease in the immunosuppressed) and chronic infections (Hoofnagle et al 2007) people who are carriers of the disease, and those affected by long-term liver damage.

¹¹⁰ <http://www.who.int/mediacentre/factsheets/fs204/en/>

¹¹¹ 5% of adults (2% of women and 7% of men); this is higher in newborns (90%) and children (30%) and those with immunodeficiency (Hoofnagle et al 2007 p.1058).

¹¹² Hepatocellular carcinoma in Europe and Asia has been associated with: male sex; advanced age; smoking; alcohol consumption; elevated liver enzyme; presence of HbeAg (particular antigen); and higher levels of viral DNA (Hoofnagle et al 2007 p.1059; Fattovitch, Bortolotti & Donato 2008).

Co-infection with HIV, prior to the introduction of HAART (highly active antiretroviral therapy) was also associated with a quicker progression to cirrhosis and a higher risk of mortality than infection with either virus alone (Fattovitch, Bortolotti & Donato 2008, p.345-346). Certain combinations of ART have subsequently been associated with reduced risk of progression in co-infected people (Fattovitch, Bortolotti & Donato 2008, p.346).

Drug therapies for treating hepatitis B are expensive (Hoofnagle et al 2007), and it is only very recently in March 2015 that the WHO published guidelines on management of chronic hepatitis B. The major public health policy for the virus is on reducing transmission through vaccination. Hepatitis B vaccine was first approved for use in the 1980's (Lok, 2000 p.90; Chen 2009 p.806) and has now been incorporated into childhood immunization programmes¹¹³ in many countries, including Uganda in 2002 (Bwogi et al 2009). Rather than targeting high risk groups (as is the policy in the UK for instance), it was found to be simpler to incorporate it into infant vaccination schedules¹¹⁴, the Expanded Programme on Immunisations (EPI) (Chen 2009, p.808). In babies born to hepatitis B carrier mothers the vaccination can prevent the development of chronic infection in children (Chen 2009, p.807). Therefore, effective vaccination can be extremely important for reducing burden of disease over time in endemic areas.

Other preventive measures are important, such as screening of blood products for transfusion. While it can be transmitted through unsafe blood transfusion, the sharing of intravenous needles, and sex, it is also associated with what are sometimes called 'low-risk behaviours', through "frequent and prolonged close

¹¹³ GAVI, The Vaccine alliance, supported hepatitis B vaccine since 2000.

¹¹⁴ Although the vaccine should be kept at 2-8 degrees Centigrade, it has been found to be relatively heat stable even at higher temperatures which has benefits for places where the cold chain cannot be guaranteed (Chen 2009 p.806).

personal contact with an infected person” often within households, suspected to be through innocuous transmission routes (Shepard et al 2006, p.114). While public health campaigns and awareness on preventing HIV transmission are likely to have had cross-over benefits for hepatitis B transmission, hepatitis B is transmitted through these other routes more easily than HIV therefore maintaining higher burdens of disease among vulnerable populations.

In studies carried out in sub-Saharan Africa, while sexual transmission remains an important route among adults, horizontal transmission in childhood appears to be a key feature of hepatitis B, with clusters of cases often found within families (Karim et al, 1988, 1989¹¹⁵; Kew 1996; Martinson et al, 1996¹¹⁶; Martinson et al 1998). Some factors that have been associated with infection include sharing personal items (bath towel or sponge, sweets, dental cleaning materials), close contact with a person who is a chronic carrier and practices such as scarification¹¹⁷ and injections from a traditional healer (Martinson et al 1998, p.484-485).

In Uganda, Hall (in Hall and Langlands 1975, p.69) described the patterns of non-specified¹¹⁸ viral hepatitis in the mid twentieth century. At this time, viral hepatitis

¹¹⁵ Karim et al report: “The lack of strong associations between these risk factors and HBV marker positivity in our data is possibly due to the high prevalence of scarification (95.6 percent) and pierced ears (90.6 percent). However, the upper limit of the 95% confidence interval for the RR of being HBV positive due to scarification is 2.1, which is consistent with associations reported in our previous study of Black children in South Africa. Possible risk factors such as scarification and pierced earlobes need to be further investigated to assess their importance in the transmission of the HBV.” (1989, p.894).

¹¹⁶ Martinson et al found in a cross-sectional survey in Ghanaian school children that among those 6 to 18 year olds tested, prevalence of markers of hepatitis B virus infection rose with age, with a peak in rate in 12 to 13 year olds, suggesting continual horizontal transmission in this age group. Martinson et al (1998) further suggested horizontal transmission by their findings from a cross-sectional survey in households in the same district in Ghana that increased prevalence appeared to occur in the age range 5 to 15 years old.

¹¹⁷ Scarification has been associated with Hepatitis B virus infection (Kew 1996, Karim et al) although it is not definitively conclusive.

¹¹⁸ We do not know the specific sero-type.

was endemic in Uganda, with additional epidemic outbreaks occurring. Hall reports that: "In 1936, a large number of cases were reported from Madi District and in 1964 and 1965 there was an epidemic in Karamoja, the infection probably introduced into Uganda by Sudanese refugees" (citing Sood, Hulley and Hutt 1966). Hall continues: "There was a further outbreak in Karamoja in 1967, and large numbers were also reported from West Nile, Teso and Kigezi Districts" (p.69). In the 1980's, viral hepatitis was also a known public health concern and suggested to be associated with the use of razor blades by herbalists (Allen, 1992). Therefore, viral hepatitis has long been known from a public health perspective as an endemic disease particularly in rural areas of Uganda, with potential for epidemic outbreaks¹¹⁹. Yet, as Allen reports in the 1980's (ibid.) the symptoms were commonly explained by people as yellow fever.

In 2005, Hepatitis B testing was included in a national HIV sero-behavioural survey of 15 to 59 year olds (Bwogi et al 2009). The authors report a stark difference between rates of hepatitis B in northern and southern regions of the country. Overall the prevalence was found to be higher in the northern districts (18.5% in West Nile, 20.7% in north central, and 23.9% in north eastern) compared to the rest of the country (3.8% in south western, 10% in western, 6.2%, 6% and 7.1%) (Bwogi et al 2009, figure 2). They found hepatitis B to be associated with rural areas, poverty, lack of education and poor health in general. The authors suggested that traditional practices such as tattooing or cutting were more prevalent in the northern districts. Additionally, they suggested that overcrowding in internally displaced camps (in the north central region affected by the Lord's Resistance Army insurgency) and overcrowding in cattle kraals (among the Karamajong of the north

¹¹⁹ WHO study published in 1980; "Hepatitis B virus can survive outside the body for at least seven days" (WHO, <http://www.who.int/mediacentre/factsheets/fs204/en/>).

eastern region) may have had a role to play in the higher rates of disease found in these areas (ibid.).

THE EMERGENCE OF HEPATITIS B IN MOYO AND ADJUMANI

In Moyo and Adjumani Districts, Hepatitis B became known as a public health problem from 2010. The district health office in Moyo had appointed a specific hepatitis B focal person whereas in Adjumani it came under the remit of the district health office in general¹²⁰. They collected data on the number of cases identified in the hospital laboratory through the hospital data reporting system.

One district staff member reflected:

We used to have people who died of liver related problems, but no specific cause was found. There was no test. When some had ultrasound changes related to hepatitis, some private clinics started to bring kits to test, which were retested at UVRI [Uganda Virus Research Institute in Entebbe]. It was then that the government started sending testing kits to the hospital.

[Interviewed 30.01.14]

In 2010, after diagnostic testing was introduced in the hospital in Moyo town and the health centre IV in Obongi town, active cases of hepatitis B were detected among people presenting to the hospital. Subsequently, in 2013 testing was also introduced at the health centre III's in each sub-county. The district staff member reported that initially the patients were people who lived in the sub-counties along

¹²⁰ This likely reflects the historical structure of the districts. Moyo had been the original district headquarters when the two areas had been administered as one district. The district health office was well-established, on the site of the original hospital which had also housed the Lutheran World Federation humanitarian organisation during the time it was operational in the area in the 1980's and 1990's. Adjumani became a separate district in 1997, and while I was living there, they were constructing new buildings to expand the various offices.

the River Nile, but subsequently patients presented from across the district, and sometimes from other districts in West Nile region, including Adjumani and Yumbe.

As the district staff member above explained, people did present with symptoms of liver disease prior to the introduction of hepatitis B testing. A laboratory worker reported that symptoms such as jaundice and ascites used to be thought of as yellow fever:

... For jaundice, people used to call it yellow fever, but now yellow fever is not heard of. [Interviewed 05.02.14]

Therefore, hepatitis as a disease did not suddenly emerge, symptoms similar to hepatitis B were present among people, but they were explained as yellow fever (for which there is a vaccine but no specific treatment). With this alternative biomedical explanation, prior to the introduction of testing, hepatitis was not considered. *“Even health workers may learn about it in school, but there was no testing, so we didn’t know”* [District staff member]. Yet since 2010 when testing was introduced it was reported to me that 58 people had been admitted to Moyo hospital with hepatitis B, of which 23 had died [District staff member].

At the time of fieldwork, it was difficult to estimate the current burden of disease among the population in the districts because testing was not widespread in government health centres. There are many barriers for people accessing testing, especially for those who live in villages far from the main towns and trading centres. A number of private clinics in the towns provided testing. In Adjumani, one clinic in particular had a large banner outside advertising that hepatitis testing and vaccination was available. However, these facilities were only accessible to those who were willing and able to pay; most likely those who lived and worked within the town. At one private clinic in Adjumani town, out of those tested for

hepatitis B between 2011 and 2014, 22.9% were found positive. At another private clinic in Adjumani town, between the end of July 2013 and beginning of February 2014, of those tested 21.1% were found to be positive¹²¹. While the available data does not give a representation of the burden of disease outside of the context of the private clinic, it provides some indication of a hidden problem in the district.

Outside of the main towns, outreach testing had been carried out at some of the fishing sites in Moyo district. The data was not available at the time, but people at the landing sites recalled the event and outcomes. Although we don't know the number of people tested, at two sites, it was reported to me by the LC's that of those tested four people at each site were found positive. To give an indication, at one site the population was about 60, although not everybody was tested.

It is also difficult to assess the patterns of chronic and acute disease, where cases are clustered, when people became infected, whether the number of cases are increasing or decreasing. At one private clinic the laboratory worker reported that they had diagnosed cases clustered within families. In one family, all the siblings were found positive (they were likely chronic carriers) suggesting either vertical transmission from mother to infants, or horizontal transmission in childhood.

Confronted with the knowledge that hepatitis was a problem in the region, the extent of which was still unknown, the response of the districts to hepatitis was constrained by a number of factors, despite their concern and efforts. There were limited finances, diagnostics, treatment and vaccine supplies particularly through the health system. In the initial period, it was reported to me that vaccinations had been brought for health workers:

¹²¹ Data kindly provided by the private clinics.

The national level released vaccines for health staff, but it was not managed here well. Not all health workers got the three doses. This was because politicians and army officers and others came for vaccines. So some health workers had to go and buy their final dose to complete the course. One injection costs 25,000 shillings. Before the government supply came, ten people, including myself, bought the first dose of vaccine from Arua. We stored it in the hospital fridge and some was stolen. Even now, there is no vaccine available. Some private clinics have it here, but not all. [District staff]

Typically, healthcare workers are high risk for hepatitis B by carrying out ‘exposure prone procedures’ such as taking blood, inserting cannulas, injections and surgery. Demand for the limited vaccinations exceeded that supplied for healthcare workers; the vaccinations had to spread much further. In contrast, for the general population, while testing was available through some health centres, vaccination was not provided and could only be obtained through private clinics. At one private clinic the laboratory worker expressed concerns over a lack of stable electricity supply for storing vaccinations¹²². While there were difficulties in the main towns, for those people along the river, far from Moyo or Adjumani towns, the problems encountered in providing, and therefore accessing diagnosis, treatment and vaccination were magnified.

My purpose is not to critique the management of hepatitis through the national health system, but to highlight the difficulties faced by the district and healthcare workers. Even more so, it is to highlight the situation of the people we spoke to in

¹²² Studies have shown that the vaccine is relatively heat stable (Jezek et al, 2009).

this research. Those living along the river were far from positions where they could access knowledge and treatment.

Along the river, without previous knowledge, hepatitis B emerged as a new disease to be feared. This became apparent at one follow-up interview from the schistosomiasis survey, as discussed in the methods chapter. A woman, Anna¹²³, had been diagnosed with schistosomiasis in the parasitological survey. Anna was pregnant at the time and therefore out of precaution, praziquantel treatment was delayed until after delivery. A month later we went back to the landing site to check up on her but we were told she was at her home. She had previously given directions to her home in order that we could see her there, so we proceeded to the village. However, she was not available that day therefore we returned the following week. Below is an extract from fieldnotes written on the day we returned to her home to meet her:

A woman has brought us chairs to sit on. She says that people are saying that Anna was found with hepatitis B. During labour, she explains, even the TBA (traditional birth attendant) and then the nurse at the health centre II would not help her here. So Anna had to go to [name] health centre III where she delivered from there. This woman says they were looking for my number to ring us to find out. Here, she says, people suspect that if someone like us comes to the home (referring to our previous visit) you must have something like hepatitis or HIV.

The research assistant explains that we are working along the Nile at the landing sites. And in fact, we did not say anything to the people at the home we spoke to last time when we came to enquire about Anna. The woman

¹²³ pseudonym

says she even went to ask those we stopped at to find out what we had said to them. But they told her we only asked for Anna, and didn't say more, except that they knew I was a doctor, as I had advised one woman who was sick to go to get treatment from the health centre.

... Anna has also returned now and says 'if someone comes to your home people think that the sickness is bad, but every sickness is bad'. She says she hadn't been aware of the rumours, 'but perhaps people were dodging me'.

[28.01.14]

In fact, it was explained to us by Anna that she had been referred from the health centre II to the health centre III because it was her seventh delivery. As there may be complications during delivery it had been written in her ante-natal care notes that she must deliver in the hospital. Indeed, the woman who had raised the suspicion confirmed to us this regulation. Despite this alternative explanation, people around had evidently re-interpreted the referral as suspicious. In the context of the uncertainties and fear surrounding this 'new disease' hepatitis, why else would a European researcher be coming to the homes of people?

A fear of hepatitis B was found to be widespread. It in part stemmed from the insidious nature of the infection:

You may have another sickness, you go to the medical, that is the time they examine you and you may be having hepatitis B [Group discussion, 11.03.14]

There is someone who went to hospital saying if he goes to sleep, the following morning he has a lot of body pains and he feels he should not get up and when he was tested he was found positive [Male, elder, local leader, group discussion, 11.03.14]

Their fear was also from the perceived severity. As one man said: *When it comes with full force, it takes you very fast...it can kill within two weeks*, [Male group discussion, 21.02.14]. Many people associated the disease with inevitable death:

But this ... one, even if you take the drugs, you die [Male elder, group discussion 19.03.14]

All we know is that once you have it, you will die [Female, group discussion 14.02.14]

And then if you are found positive you must wait to die [Female, group discussion 18.02.14]

Within six months, you see someone developing swollen stomach and then he dies [Female, group discussion 20.02.14]

Comments such as these came up in nearly every discussion on hepatitis. It also became clear that hepatitis was often heard about in relation to death, with funerals being a key time for people to find out information. Information and health messages surrounding hepatitis were being disseminated. Obongi health centre IV displayed a detailed hand written poster in the waiting room area. There were bulletins on local and national radio stations. Yet it was often through funerals that people understood the impact and significance of hepatitis. Even if people had not seen others suffering with hepatitis, many had attended funerals of relatives who had died of the disease. One group of women discussed the health information passed on at funerals:

We usually get given this information [about how hepatitis is passed on from person to person] during burial time, not through community health sensitisation. The medical person comes to the burial, they come with gloves and tell the people not to touch the body directly. That's when they sensitise. [Female group discussion, 19.02.14]

Within the first few days of my arrival in Adjumani, a funeral of someone who had died of hepatitis took place. Some people were reluctant to attend the funeral having heard how easily hepatitis is transmitted. They decided to 'monitor from afar'; that is, to be in the vicinity of the home as the funeral proceedings took place but rather than sit within the congregating mourners, they sat at a nearby home. Thereby fulfilling their social obligation to be present, but minimising the perceived risk of being in close attendance.

Normally, when somebody died the body was brought back to the home. Men, including the in-laws, assisted in digging the grave while women prepared food for the guests. The body was washed and laid out and usually the burial took place within a day or two of the death. However, when someone had died of hepatitis, things were different. People described that when the body was brought home, they were advised by health staff to have minimal contact with the body. When washing and preparing the body, they were told to wear gloves and as few people as possible were to have contact with the body. The burial often took place very quickly. As one man reported:

A few have gone from here for the funeral (of someone who died with hepatitis B), but they reached there and the burial had already taken place. [Male, group discussion 19.03.14]

The surreptitious nature of the virus and the disease, the severity and danger it posed, and precautions surrounding funeral arrangements all bore resemblance with the emergence of HIV in the 1990's. Yet just as hepatitis suddenly emerged as the new HIV, for those we spoke with along the river, liver disease (*laza logo*; *laza* meaning sickness or affliction, *logo* meaning liver) in general was widely known about prior to this. The symptoms of *laza logo* (yellow eyes and palms of jaundice, swollen abdomen, vomiting blood) had been associated with many illnesses, including forms of local poisoning, yellow fever, intestinal worms like schistosomiasis, and alcohol.

One man reflected on associations with local poisoning and witchcraft:

In the past, people could die. Now, you could say hepatitis was there and they died from it. But people didn't know, because they were not examined. So people died in hospital and at home and were buried. Those days, they might have said 'so and so was poisoned', but nobody had the chance to find out what was causing it. Maybe now you could say it was hepatitis. [Male, discussion 11.02.14]

Other associations were made with yellow fever:

Hepatitis B should've been there in the past but some people didn't know what it was. The symptoms they talk about were even there in the past; like liver, severe headache, eyes turning yellow. These used to be there except people didn't know it was hepatitis. It used to be called yellow fever. It used to be, people having swollen stomach and they would first go to the witch doctor or for local herbs and it would fail and they would go to the medical. In the 1990's this was happening. These days, it is now realised because

there are so many sicknesses coming, they first try the medical. [Male, group discussion 11.03.14]

Both these quotes demonstrate how not only had similar illnesses been present before, but also how people were re-evaluating these past explanations for the symptoms given current circumstances. The second quote also suggests that both local and biomedical treatment were used for treating symptoms of liver disease. While this man suggested that local treatment failed, in another discussion it was suggested that the illness, yellow fever, was curable:

In the past they used to use local herbs for yellow eyes, that which was yellow fever, and the herbalist would say 'don't eat oil, and eat greens'. That one can get cured. [Group discussion, 17.03.14]

From a biomedical perspective, yellow fever and hepatitis B can either resolve or lead to severe disease and be fatal, which likely leads to more uncertainty surrounding the disease. Similar to the current status of hepatitis B in the districts, there was no biomedical treatment for yellow fever.

Liver disease was also associated with other conditions, including bilharzia, intestinal worms and alcohol consumption. While bilharzia causes a different set of internal biomedical problems to hepatitis from viral causes or alcohol, they were seen as externally indistinguishable causes of *laza logo*, at least until hepatitis B testing was introduced.

During those days, the equipment was not there to detect what kind of sickness it was, so you may have liver cirrhosis, but they will say it is worms. There was no equipment to check. And then you die. But these days, this equipment is there to detect the disease. [Male group discussion, 18.02.14]

Even so, in trying to make sense of the illnesses and information given to them, the often cited causes of liver disease were questioned.

Some people say you vomit blood or have liver or heart problem because of alcohol. But a small child can have the same problem. How can they say it is because of waragi? Or they say it is because you are thinking too much, you have too many worries. But what of the small child? How can you say they are thinking too much or have too many worries? [Female group discussion, 18.02.14]

The men at the same landing site responded in a similar way. They also wondered if it was the new forms of alcohol being sold. Previously, people drank locally brewed beers from sorghum or millet, or *waragi* distilled from cassava. More recently, strong alcohol like whiskey or vodka, were being sold in small plastic sachets.

If people say it is the alcohol, in the past they drank local brew, now it is these sachets. They were drinking in the past, not less than now, but it was local brew. But this present waragi is dry. [Male group discussion, 18.02.14]

At the landing sites, these alcohol sachets were often seen. Sometimes fishermen went out to the river with a few in their pockets. It was once commented on by a fisherman and BMU member, that despite being so remote, those who sell these sachets (transported in a small truck) knew all these fishing sites. In some places in Obongi where the majority were Muslim, alcohol was less common. And on one Madi fishing island, alcohol in any form had been banned. However, these sachets of alcohol were seen by many as having caused not only social, but health problems.

There was therefore some uncertainty of understanding the different causes of liver disease. Because of this there was some confusion surrounding hepatitis. During some of our discussions, people talked about hepatitis as a disease they had heard about on the radio or by word of mouth, but had not seen themselves. Yet when asked directly, 'what about liver disease?' some people replied, 'now liver disease, that is a problem here', and recounted people known to them who had been diagnosed.

This was illustrated in one discussion with a group of fishermen [on 19.03.14] while discussing bilharzia:

'Bilharzia used to be a big problem but since the mass treatment it is not so much. Now it is malaria that is still a problem. But we also hear of this one, hepatitis B.' One man has heard of someone dying, but has not seen it. They say they don't know about it. One has heard rumours that it is got from the air. No one goes for testing. They have only heard that so and so has died, but not here, in [village].

However, when I then asked about liver disease, they said:

'Liver disease is common here, five people have died. It has stayed over three to four years.' One man has forgotten how they get it; 'perhaps it is from dirty water'. Another man says 'the daktari (doctor) says bilharzia can cause it, and dirty water...

'Those with liver disease go to town (Adjumani) so we don't hear here about it here.'

Despite the confusions surrounding hepatitis and liver disease more generally, people had heard a lot about the disease. Cautious healthcare messages had been

provided. Often people were told not to share cutlery and food with those found positive. This was contrary to normal customs when eating where people shared from the same bowl or plate. Particularly in the past, when offering food, the person offering would take a small piece first to demonstrate that it hadn't been poisoned. That said, during fieldwork we didn't come across a time when people feared sharing food because of hepatitis. However, these healthcare messages were often recited during the discussions. Other forms of transmission were noted. Sometimes this could be related to social authority, and people expressing concerns over the increasing trend for videos and discos in the larger trading centres.

For hepatitis, you mainly get it through body contact such as at the video. The health personnel advise you not to go from one to another with Slim (HIV). For hepatitis it is passed through body contact and sex.

It was therefore known to be transmitted through sexual relationships similar to HIV,

We were told how it is passed: either sexually or bodily contact with fluids, even saliva. [Female group discussion, 19.02.14]

But also through subtler means,

It is spread through the shaking of hands, sharing clothes and sexually transmitted. [Male group discussion, 21.02.14]

You can easily contract it when you get contact with the sweat of the positive patient. [Female group discussion, 28.02.14]

Nobody linked transmission with the use of razor blades and cutting by local herbalists, although this would likely have been a route of transmission especially in

the past. Awareness of HIV has led to changes in practices and as discussed in the previous chapter, it was reported that herbalists advised people to bring their own razor blade to be used solely for them, specifically for avoiding blood-borne infections like HIV (and therefore hepatitis B).

With these being the routes of transmission, on being tested one group of women reported:

Once you are found positive, you will not be accepted in the community. They will not accept for you to sit with them, share food, or talk with them. Where you spit saliva; that should be separate. You should use separate utensils. [Female group discussion, 19.02.14]

However, they went on to admit that there had not been somebody found positive within their villages and so they had not experienced this happening. Yet similar accounts were heard from most discussions and interviews on the issue. One woman had gone for testing with her sister-in-law. Her sister-in-law was found positive and they had been told she must sleep alone in her own bed, and she was advised to use separate utensils and cups [Female group discussion, 28.02.14].

Others reported:

If they are tested positive, they should stay alone, not shake hands with anybody, not share utensils, and not sleep side by side with anybody [Female group discussion 20.02.14]

Caring for those found positive they say that someone who is positive should remain in hospital until he finishes the treatment and then come home. At home, they should be fed on a good diet, and hygiene, of keeping him or her alone without contact with others. [Male group discussion, 21.02.14]

We only hear on the radio: you should not mix with a stranger, especially with the refugees that have come as they may have come with it; and from Arua as well. [Male group discussion, 27.02.14, at a fishing site near a new refugee settlement]

Once found with it, you should not stay with people, you should not be touched, and not share things. Only use your own things and that is for you. [Male group discussion, 01.03.14]

We have heard that if you have hepatitis you should not meet with your husband if you are a woman, or your wife if you are a man; there should be no sex. [Mixed group discussion, 17.03.14]

These quotes demonstrate the fear that hepatitis B conjures – that it may be transmitted with the slightest contact and that people should be wary of strangers. In another case, someone discussed a man in the village who had been diagnosed with hepatitis B:

There is not much sensitisation. But what they hear in rumours is that you should not shake hands, should not share rooms, should not share utensils. The person (who had been found positive for hepatitis B), he started getting the treatment but it seems he doesn't follow, because when he sees you he gives his hand to shake. [Male elder, group discussion 11.03.14]

As this last man said, it is however ‘what they hear in rumours’. There had been limited, at least not long-term, knowledge on the subject and therefore the fear created from people’s experiences of death and information from healthcare messages merged in a way that fostered more fear and uncertainty.

However, there were a few people I spoke to at the fishing sites who had acquired biomedical knowledge of the disease. One man had learnt about hepatitis through an HIV support group that he was a member of, and gave a relatively detailed account of the five types of viral hepatitis. Two other fishermen I spoke with in Adjumani district had heard the information across the river in Moyo district, and one of the men had a brother who was a health worker. The majority of people however pieced together information from various sources, from healthcare education messages, from rumours, from funerals.

At one of the fishing sites however, an elder was very involved in organising the people of his village to attend for outreach testing and he took a great interest in the health of people and local hygiene matters. There was a programme for outreach testing in their village, and four people were found positive for hepatitis. He managed this by encouraging openness, rather than separation:

I gathered people and gave out the names, saying do not fear, stay with them, chatter and eat with them [13.03.14]

He wanted to avoid people being ostracised. Yet the majority of people recited opposite management strategies. Despite the way the majority of people talked about the disease, I did not hear accounts of people being avoided because of hepatitis B, although we only spoke to a few people at the sites who had been diagnosed. Few people at the landing sites had actually tested for hepatitis, and so much of the experience of hepatitis B described by people was second-hand experience. Yet, the way that people talked about hepatitis B does raise questions on what the social effects of the virus might be, given the confusion, fear and uncertainty it has brought.

In light of the emergence of hepatitis B, many people re-evaluated past sicknesses that had been associated with liver disease. Yet while hepatitis can cause severe and acute illness and visible signs of liver disease, the other side to disease both in terms of its transmission and symptoms, is the insidious nature of the disease; its silence. A person may not know that they have a disease, but on testing they are found to be positive for hepatitis. With this uncertainty and quest for knowledge for understanding this new disease, how did people make sense of hepatitis B? The following sections show how social responses to this new phenomenon drew on many experiences, in particular from understandings of HIV/AIDS and witchcraft.

‘MORE DANGEROUS THAN HIV’

In contrast to hepatitis B, HIV prevalence has consistently been reported to be lower in West Nile compared to many other regions in Uganda. While there are no doubt limitations to the survey methods used to estimate figures, a 2013¹²⁴ Uganda HIV and AIDS Country Progress report, reported that prevalence in West Nile was 4.9 (compared to 2.3 in 2004-2005) (p.2). This is in comparison to other areas particularly Central Uganda where it was 9.8 in 2011 and North Central where it was 8.3. It was a well-known disease even in the early 1990’s. Interestingly, a survey by MSF¹²⁵ quoted in Allen (2006) in Moyo district in 1991 found that 90% of the participants had heard of HIV/AIDS (p.22). People were acutely aware of the disease at the time.

HIV is also known as ‘Slim’, or ‘*urwea*’ in Madi, due to the weight loss that was typically seen (especially prior to ARVs). Perceptions of HIV had changed over the previous twenty years, especially with the introduction of antiretroviral therapy,

¹²⁴ The Republic of Uganda, (2014) HIV/AIDS Uganda Country Progress Report; 2013.

¹²⁵ Schopper, D. (1991) Aids-Related Knowledge, Attitudes and Behaviours in Moyo District, Northern Uganda, MSF-Switzerland, Kampala.

ARVs. Hepatitis B was often likened to this initial period of the HIV epidemic, and now in fact superseded it.

Mostly people talk about HIV and the present sickness that has followed HIV, the one which is feared most. [Male, interviewed 11.02.14]

It is more dangerous than HIV. [Male, group discussion 21.02.14]

Many of the social responses discussed in the previous section also corresponded to the initial period of HIV.

Most people die of this hepatitis B because of not knowing it and it becomes like AIDS. When AIDS first came, people feared you; they abandoned you. [Male, local leader, group discussion 13.03.14]

For us when Slim came, Slim was also said to be like that: very dangerous. But when people talk about Slim, they say how to take care of it and people know it can be managed. But hepatitis B, no one has said. So now we are more worried about hepatitis. [Male, group discussion 14.03.14]

One of the biggest fears with hepatitis B comes from a lack of knowledge. While it was thought as 'deadly' and 'rampant', in fact, very little was known about the extent of the disease in these areas. People had heard about hepatitis through various means, yet few had tested, at least not systematically. Many questioned why they are not being tested as for HIV, and why it is not being managed as HIV is:

The problem is they are talking of hepatitis B, but they don't want to come as with AIDS and test openly. [Female, group discussion 18.02.14]

They have not sensitised the community on hepatitis like that of Slim. [Male, group discussion 14.03.14]

This 'sensitisation', or information giving, often came when people attended funerals of somebody who had died of hepatitis B. This was again an experience that echoed funerals that took place in the 1990's for people who died from HIV/AIDS:

If you die, the medical personnel bring the body to the burial, it is kept in the ambulance whilst the grave is dug and the medical personnel put the body in the grave. No one is allowed in the house where the dead body is, because the fume, you may smell it, and get the attack.

From the beginning of Slim, in 1993, it was like that. They laugh: The body would not be touched; it would be pushed into the grave with a stick. In one place, one home, nine people died of Slim. If you are drunk you should not cross that home because you will trip and fall over the graves. [Men, group discussion 21.02.14]

Whereas HIV had once been a disease much feared, hepatitis B had taken its place, and now in relation to hepatitis B, HIV was a manageable condition that people lived with.

[Hepatitis] is worse than Slim. Slim has no strength now. Even if you are found positive, you produce a child who will be negative. There is no problem now. During those days (10 / 20 years ago), there was no drug (ARVs), but now with the drug, you can stay for 50 years. So we don't worry so much now. [Male group discussion 27.02.14]

AIDS does not kill you itself; it is the other sicknesses it brings that kill. But if you are serious, you can get rid of that one, and then that one. You can do ok. [Men, group discussion 21.02.14]

Hepatitis doesn't spare you, it will kill you. But for HIV, if you take the drugs you are ok. [Female, interviewed 11.02.14]

These perceptions have changed since 2009. When I was carrying out fieldwork along the river during 2009, although I was predominantly looking at schistosomiasis again, we also had many general conversations about HIV/AIDS. At that time, a number of people questioned why the health services didn't make it mandatory to test for HIV, and some even requested that the health services organised testing in the community 'house to house' (*jo ti si, jo ti si*) as they do for distributing the drugs in mass drug administration. It is interesting that four to five years later some people compared HIV to malaria. Their concerns had shifted to hepatitis. Part of this is likely due to the widespread availability of ARV for HIV. It is also arguably therefore because of the lack of widespread testing and treatment for hepatitis B, and in addition, the nature of hepatitis B transmission. The healthcare messages that have been taken up by people have only served to reinforce this.

But those with HIV, we would shake hands with. The AIDS of those days (at the beginning when it was first known about) people used to fear, before ARVs, it would be a short time before you died (perhaps six months). But when the drugs came, people stayed and they treat it like malaria. But hepatitis B, it spreads quickly. For HIV, even if you stay with someone and don't have sexual contact, you will be ok. But hepatitis, even if you don't have sexual contact, it will spread in other ways. That time (with HIV), when drugs became available, people would go for testing so you can take the drugs. But hepatitis, there is no drug, but you still go, to know if you are going to die soon and to avoid other deaths in your family if you are positive. [Female, interviewed 11.02.14]

The points made here in relation to the availability of biomedical healthcare are discussed in the following section. The similarities with initial experiences of HIV are striking though. HIV has shaped responses to hepatitis B, and likely even vice versa. Yet, as was discussed in chapter three, when it first became known, understandings of HIV/AIDS were shaped by understandings of witchcraft and poisoning. This was also the case for hepatitis B.

In some instances, hepatitis was linked to witchcraft and witchdoctors were approached for treatment alongside, or instead of, biomedical treatment, illustrating a pragmatic approach to uncertainty (Whyte, 1997). This was found at one particular landing site where witchdoctors were commonly consulted for certain sicknesses. An elder and local leader, Saidh¹²⁶, at this fishing site discussed two recent cases and explained to us about consulting witchdoctors for hepatitis¹²⁷.

Another thing is that when someone comes sick from hepatitis and is not examined in the medical facilities. They may instead go for witchcraft and the witch doctor may misinform them and begin performing rituals and giving local herbs. And the person dies, leaving others also with the sickness.

It happened here. The person was found positive in Arua, but then because the condition was now worsening the parents decided to believe in witches and took him to the witch doctor and the patient later died.

Both Saidh and later Aisha, the wife of this man who had died, explained to us about her husband's death six months previously. Her husband had had no sign of a swollen stomach, or vomiting, but had been complaining of headaches and stomach ache. The medical doctors diagnosed hepatitis. Aisha's mother-in-law

¹²⁶ pseudonym

¹²⁷ Discussions, 07.03.2014 and 10.13.2014.

along with his family had taken him to Arua to confirm the diagnosis. The family knew a doctor in Kampala who they rang for further advice. The doctor advised them to take the man to Kampala for further investigations and treatment. However, the mother-in-law explained that local poisoning can cause his symptoms and so he was taken to one witch doctor in Yumbe and another nearer to their home. When the man began taking local herbs he felt better compared to how he had felt on *erua Mundro*. As Aisha explained, *“If someone feels better on local herbs, then they think you should continue, and not use erua Mundro. If we had been advised properly about hepatitis, we could have continued with proper medicines.”*

When her mother-in-law and husband returned, they explained to Aisha that the sickness was hepatitis, but they continued using local herbs alone. Aisha was advised: *“one, he should sleep alone; two, he should eat alone; three, his utensils should be used only by him.”* She was not aware of what hepatitis was and hadn't been given any more of an explanation. As she explained:

“I sometimes thought of local things that worked on him because no one has told us clearly what hepatitis is and how it is passed or affects you. So people at home and myself started thinking of local poisoning. We couldn't suspect anyone as this local poison can happen to anyone. He had quarrels with his father, but not to have caused this.

When he was on local herbs he improved and when he took medicines from the hospital he got worse so we thought of local poisoning; as this is what happens.”

Her husband died whilst at the witch doctors home. The family and Saidh brought him back to their home that same night. His body was washed and prepared, as per

usual customs. There was no involvement by the healthcare workers, no special precautions such as gloves, as many others reported to be the case at funerals.

Saidh explained about a form of witchcraft, *Maji*, which was said to have come from Congo. It was said to have been around since Idi Amin's regime, but came to the area he lived in during the 2000's. *"It is a kind of devil spirit that you cannot see but it passes into you and goes to the liver (he points to his abdomen) and it affects you and makes you vomit blood. If you are vomiting blood, then it is Maji."* The difference between liver disease from biomedical causes and *Maji*, it was explained to me, was that *Maji* is inflicted on a person by another. The symptoms were the same.

Saidh had worked with the local health staff at times when there had been outbreaks of disease, for instance meningitis or cholera. He tried to distance himself from the practices of witchdoctors. *"For me, I do not want witchcraft or witchdoctors. And it is money. These witchdoctors are expensive; they ask you to pay three to four hundred thousand shillings¹²⁸",* fees that were often paid for by selling goats or cattle owned by the family or clan.

Saidh explained the situation for Aisha's husband¹²⁹:

... the problem was the mother who believed in these things of witchcraft and local poisoning and there were allegations made about a certain man.

The dying man had even said to me, when the mother and family were not around, that he was going to die from this. But the man had no power. But even this woman (Aisha) is somehow aware. She has received sensitisation about the disease. And the family are rich. That is why they were able to

¹²⁸ Approximately £80 – £105 at the time.

¹²⁹ Speaking in English.

link up with the doctor in Kampala. In fact, they even wanted the man to be transferred from Arua to Kampala but the mother-in-law said to take him to the witchdoctor and it was after that that the man said, 'I am going to die from this.'

In this case, the family pursued both a biomedical route for managing the disease, as well as drawing on understandings of witchcraft and poisoning. This was more apparent in the area where Saidh and Aisha lived. In many areas, hepatitis B was first and foremost discussed with me in regards to a biomedical disease, with people predominantly understanding hepatitis by drawing on their previous experiences of HIV. However, it was also clear that in the past, the illness *laza logo* had been understood as a form of local poisoning and even when thought of as yellow fever (with no biomedical treatment) it was treated with local herbs. To some extent at least this appears to be the case today with *laza logo* and hepatitis. As illustrated throughout this discussion so far, the limited access to testing and treatment only adds to the confusion and uncertainty surrounding the disease and, as we will see in the following section, trust in biomedical healthcare.

HEPATITIS AND HEALTHCARE

Hepatitis B has been conceptualised and understood as an emerging disease, with a reconsideration of past illnesses and afflictions. The varied nature of the disease in terms of its transmission routes and severity enhances people's fear and uncertainty. While there is some resort to witchcraft causality to explain the sickness, a large part of people's quest to understand hepatitis B draws on their experiences of HIV. Within this there is a positive perception on the effects of antiretroviral therapy for HIV. HIV is no longer a disease to be feared, in comparison to hepatitis B.

Whyte (1997) analysed the uncertainties that came with AIDS in eastern Uganda in the 1990's. These uncertainties were not only with the disease itself, but also with the provision of biomedical healthcare. For hepatitis B, accessing treatment was extremely difficult. This lack of access to treatment, and first and foremost testing, has had wider consequences, feeding into the chaos and fear that surrounds hepatitis, but also into the mistrust and dissatisfaction with the provision of health services more generally. As has been discussed earlier, the difficulties experienced in the towns are magnified in the areas along the river.

The test for hepatitis B is a reagent strip test for HBsAg, Hepatitis B surface antigen, which shows positive in current infections. These current infections include those who are chronic carriers and those who have an acute infection. People found positive therefore, are often told that there are two types of the infection. People understood these two types (chronic carriers and fulminant hepatitis) through the outcomes. The first is one which doesn't require treatment, but *'if you eat greens (osobi) you will be ok'*. Following outreach testing, "One was positive but at a low stage - if that person ate greens it would clear it off" [Male group discussion, 07.03.14]. For the second type, *'if you are found positive, you die within six months'*. Those found positive were therefore given advice on diet and hygiene, typically to avoid meat, oil and salt, and to eat plenty of greens and fruits. One woman recalled the advice given to her when her test results were positive: *'if I reach three months and six months then I will be ok'*.

However, accessing testing in the first place was problematic for some. People frequently requested that testing should be provided as it is for HIV, free and readily available. At one site where they had received outreach testing, this was an opportunity which the majority took up, although some did avoid it according to a local leader. When there was an outreach programme for testing in the village

centre or at the landing site, overwhelmingly people welcomed it and took the test. At many sites people requested for outreach testing: *'If we are not tested and the disease comes here, we will be finished, so we want to test'*. [Female, group discussion 14.03.14]. Some people did test opportunistically. One woman reported that she had gone to the market in the trading centre to sell her fish, and found that they were testing so she went for the test. Yet when the testing was only available at the health centre, people's response and experience was more varied.

While at some sites people reported that they had gone for testing, others did not. One woman was concerned about the reluctance to test:

The problem is no one can get tested as here there is no talk of testing. But when you go to Obongi, you hear they are testing so you get tested. But here I am worried why people here are not testing. What is going on?

[Female, elder, group discussion 19.03.14]

Testing had been made available in health centre III's. In many areas the nearest government health centre did not provide hepatitis B testing as they were grade II health centres. Yet even at a health centre III near the river sites they experienced problems. In one health centre III the acting in-charge health professional reported that they had initially begun with outreach testing in the community, but because there was a low stock of testing materials they changed to only testing those suspected to have hepatitis who attended the health centre. This was also noticed in another area:

Testing for hepatitis first started in the hospital freely, but then they abandoned it, [maybe] because people were too many and they decided to say the machine has broken down. But what I know is, in [a nearby] health

centre, the testing is there, free. [Another nearby health centre] doesn't have testing [Female group discussion, 20.02.14]

There was not only confusion because testing was not always available at the health centres. Some people had had experiences where they had been found positive at one health centre, but negative at another, leading to questions on the reliability of the testing at the local health centres. In one area¹³⁰ in particular people questioned the testing: *'is the reagent out of date', 'does it really work'?* These experiences were discussed at one site in particular:

They came for outreach here, under the tree at the market area, to test for hepatitis in December 2013. Some were found positive. They went to [a health centre in a town], positive. They took them to [a large town in a neighbouring district], there was nothing. They went to Kampala, nothing. They used their own money, more than 300,000 shillings. This is why we don't trust them here in [town] or [sub-county]. [Female group discussion, 06.03.14]

Although we tried we did not manage to follow up on those who had been tested and found positive at the initial outreach session discussed here. However, there is a possible alternative biological explanation for the discrepancies in test results discussed above. The common test used for hepatitis B detects HbsAg which is positive in acute infections, and remains positive after six months in chronic carriers (a defining feature for chronicity)¹³¹. Therefore, one explanation is that those tested through the outreach programme had acute infections, which later did not develop into the biological state of chronic carrier. Either way, the issue here is

¹³⁰ For confidentiality the site is not named.

¹³¹ <http://www.who.int/mediacentre/factsheets/fs204/en/>

how these experiences were interpreted. Where health service provision was perceived as inadequate, these inconsistencies and uncertainties were seen as a failure of the local health services. This was sometimes explained by people by out of date testing kits, and fed into a mistrust of health services locally.

This mistrust of the testing was not just seen for hepatitis B, it was also expressed towards our own parasitological survey. Some people expressed doubts over the machinery: '*was the microscope working?*'; '*was the equipment out of date?*' These doubts came about because of a dissatisfaction with the outcomes. Many of those tested had been experiencing intestinal symptoms, which were a common complaint, and yet they were not found to have bilharzia. These experiences influenced the social responses to local biomedical healthcare in whatever way it is delivered – through the public health system, through vertical interventions or research programmes.

At other sites people reported that the hepatitis B test was not free, which prevented many from testing. Initially it was only available in the private clinics, and even at the time of fieldwork, in some areas this remained the case. However, the challenges went beyond the provision of testing. As one woman explained:

Those who have money test. Because, if you are negative, one injection is 30,000 shillings. In hospital the test is free, in the clinic it is 5000 shillings. The injection is not free in either hospital or clinic. So people fear going for testing, even if they go for free testing, if they are found negative, now you have to find money to get the injection. So people in the village don't go.

[Female group discussion, 20.02.14]

Therefore, whether testing is freely available or not is not the only barrier for people. One problem at the time of fieldwork was that treatment was not available

through the public healthcare system (discussed with many doctors and health workers). Even when people went for testing, whether found positive or negative for hepatitis B, they needed to purchase treatment (commonly people were advised to buy 'Liv 52', a herbal based treatment that was only available in the private clinics) or vaccination. For both, even if they were physically available in a private clinic, they were deemed unaffordable. As one woman explained:

Going to test, people don't worry about, but once it is tested, you get worried. [Female, group discussion, 28.02.14]

Two men who had gone for testing, described their predicament:

We have been tested and found negative. But we need treatment. But it is 90,000 shillings (a vaccination course includes three injections, each costing 30,000 shillings). But a child needs to go to school, the family needs feeding. If you go yourself and get treated (vaccinated) they say you also treat the whole family, which may be five people with a wife and children. How can you manage? [Male, group discussion, 21.02.14]

While it is reassuring for people to know their disease status, this is only the beginning of the problem for them. One woman questioned the lack of vaccination in the health centres:

Why is it that the government does not bring the drugs for those found negative? Why is the government waiting to bring the vaccines? If you are found positive, there are no drugs, you just wait to die. But if you are negative you should be protected. [Female, group discussion, 19.02.14]

It is worth noting here that there has been a response by the Ministry of Health. Hepatitis B vaccination was introduced into the Expanded Programme for

Immunisations in children in 2002. Therefore, future generations who have been vaccinated will be protected. But those who are older and did not receive hepatitis B in their childhood vaccination schedules are understandably concerned with this emerging disease. Aside from vaccinations, treatment of hepatitis B virus was even further out of reach.

The advice given is that it depends on the range. If it is plus plus, you can be put on ARV (antiretrovirals). If not plus plus, you can use greens, paw paw, and fruits. [Male elder and local leader, group discussion 13.03.14]

As the elder quoted above said, ARVs can be useful in some instances for liver disease from hepatitis B. However, the reality was that ARVs were managed through HIV clinics which were at the time co-organised by 'Baylor' (BIPAI-Uganda, a PEPFAR funded US organisation) through the health centres, in effect they ran as a semi-autonomous clinic within the healthcare system. Parallels can be seen with what Harper and Parker describe for hepatitis C in Nepal (2014, p.199). Here, the co-epidemic was set aside with funding ring-fenced for HIV, TB and malaria. As a doctor in northern Uganda pointed out to me, those who have liver disease from hepatitis B are better off if they also have HIV as they can access treatment¹³². For people in Moyo and Adjumani, while they overwhelmingly drew on their experiences of HIV to understand the new disease hepatitis B, the public health response did not yet match that for HIV in terms of biomedical testing and treatment.

Having discussed people's responses to the emerging disease, in the concluding section, I reflect on hepatitis B in relation to the lens of neglected tropical diseases in global health.

¹³²I am grateful to Dr Nicholas Laing for pointing this out (personal communication).

CONCLUSIONS: RE-EVALUATING NEGLECT IN GLOBAL HEALTH

Juxtaposed to Buruli ulcer, hepatitis B is not a 'neglected tropical disease' but arguably it is an emerging public health concern, from both a global health and local perspective. Hepatitis B was even being described as a neglected disease by doctors in the district. It has arguably been neglected in northwestern Uganda until recent years. Viral hepatitis and hepatitis B have been described as 'silent epidemics' from two main positions. While the WHO has described viral hepatitis as a biological silence (2013), Muraskin (1988) argued that it was a social silence that led to hepatitis B being "the silent epidemic" (1988) in the U.S three decades ago. He sought to explain why viral hepatitis received relatively little attention in terms of awareness and understanding as a major public health threat, arguing that the 'medical community', at the time being the only at risk group (among also homosexuals, intravenous drug users, the Army and the media) that could effectively mobilise and present the infection as a public health concern (and not a private, silent one), did not.

However, from a global health perspective, viral hepatitis was officially acknowledged as a global health concern in the 63rd World Health Assembly in 2010 (resolution WHA 63.18), the same year that it was acknowledged as a public health concern in Moyo and Adjumani districts. Prior to this it was arguably overlooked as a global health priority. Additionally, it disproportionately affects poor, marginalized populations. Paul Farmer writes, "...framing NTDs in competition with the "big three" or maternal and child health or any other key global health priorities is misguided. Most of these areas are complementary; all of them are critical" ... "many of these diseases are controlled in affluent countries and neglected in poor ones." (Farmer et al 2013, p.314). Hepatitis B still disproportionately affects poor, marginalised people in affluent countries like the US or UK (Muraskin, 1988).

In questioning the definition of neglect in neglected tropical diseases, Broadbent suggests: “the differential availability of existing curative and preventive measures between populations” (2011). For hepatitis, the neglect goes beyond the availability of curative or preventative measures. Although these are factors, first and foremost there is a lack of testing and knowledge. The question is not just what is neglected, but why and how?

I suggest it is a form of structural violence that has allowed a well-known disease to become an emerging, silent epidemic. In Moyo and Adjumani districts, the health system manages multiple disease specific programmes co-ordinated by district staff. Many of these priorities, like neglected tropical diseases, are focussed by global health initiatives, of which until recently hepatitis was not one. While the government health system has implemented some measures (predominantly vaccination programmes which will have long-term benefits), there are constraints within the under financed, under serviced health care system. The public health system went some way to addressing the problem with the introduction of testing in government facilities, but at the time of fieldwork this did not reach all those who were vulnerable. While Moyo district implemented additional outreach testing, both districts were working within ongoing constraints on the public health system. At the time of fieldwork, provision of testing and even more so treatment was inadequate on a population scale, as only those who could afford it could access it through private clinics in the main towns. People living in rural areas, which are likely to have high burden of disease, had been left with few options (Bwogi et al, 2009).

Historical factors are likely to have exacerbated the disparities in northwestern Uganda. As speculated by Bwogi et al (2007), the impact of decades of conflict in the northern regions may well have influenced the scope of the problem with

overcrowding in internally displaced camps leading to increased transmission. Provision of healthcare was undoubtedly difficult during the years of conflict, and while only certain areas of Moyo and Adjumani were directly affected and displaced by the Lord's Resistance Army, the region as a whole was relatively cut off during the time of the conflict. Older generations have also had experience of living in refugee camps in southern Sudan during the 1980's, which may have led to similar vulnerability to hepatitis B transmission.

Previous blood transfusions, prior to the introduction of a systematised blood bank with pre-transfusion screening for blood borne viruses like hepatitis B are also likely to have shaped the patterns of hepatitis seen today. Bwogi et al (2007) found that having had a blood transfusion more than fifteen years previously was a risk factor associated with hepatitis B. Nobody during fieldwork linked hepatitis B to razor blades and local treatment with cutting. The risk could well have reduced, if there is more care on razor blade use by local herbalists. But in the past, this is likely to have been a factor that aided the transmission of hepatitis B (as suggested in Allen, 1992).

These factors together no doubt explain part of the situation that is found in northwestern Uganda today with the high rates of hepatitis B. However, rather than the biological silence that the WHO have remarked on, and the social silence that Muraskin describes, my suggestion here is that the other aspect to this has been a structural silence. In terms of a global health response, it is only very recently that hepatitis B has been receiving increased attention. There has in fact been a very recent shift in the place of viral hepatitis in global health. Following the World Health Assembly resolution, in 2010 viral hepatitis was officially recognised

as a global public health problem¹³³ and World Hepatitis Day was assigned to be on the 28th of July each year (WHO 2013 p.2). Following fieldwork, global health priorities have been changing. In fact, in 2014¹³⁴ the theme¹³⁵ for World Hepatitis Day was to “‘Think again' about this silent killer”¹³⁶. World Hepatitis Day 2014 in Uganda was officially celebrated in Adjumani District. In March 2015, the WHO published its first guidelines on managing chronic hepatitis B¹³⁷, and in September 2015, the first World Hepatitis Summit will be held in Glasgow, Scotland. The Summit programme states that it will discuss some key issues such as opportunities for global health funding for viral hepatitis, and its management through healthcare systems (by adequate screening of blood products, and testing, vaccination and treatment provision) rather than vertical programmes¹³⁸. More recently, the Ugandan government has announced that it will be providing vaccination for older age groups, and obligatory testing for healthcare workers (New Vision July 28th2015¹³⁹). Little has been said yet on treatment.

With these recent events, from a global health perspective, the silence is being acknowledged. These fieldwork findings and the discussion in this chapter are

¹³³ WHO guidelines for raising awareness of viral hepatitis and strategies for its prevention and control follow the following (WHO 2013, p.2):

1. Awareness-raising, Partnerships and Resource Mobilization
2. Evidence-based Policy and Data for Action
3. Prevention of Transmission
4. Screening, Care and Treatment.

¹³⁴ See the WHO Global Scaling up meeting in April 2014 on viral hepatitis (<http://www.who.int/hiv/pub/hepatitis/WHOScaling-up-action-for-Global-Hepatitis-Prevention-and-Treatment.pdf?ua=1>). In their presentation slide they link to important lessons from HIV scaling up.

¹³⁵ The theme in 2015 was on prevention: “Prevent hepatitis: it’s up to you”

¹³⁶ <http://www.who.int/campaigns/hepatitis-day/2014/event/en/>

¹³⁷ “WHO guidelines for the prevention, care and treatment of persons living with chronic hepatitis B infection”

¹³⁸ <http://www.worldhepatitisummit.com/programme/>

¹³⁹ Mass Hepatitis B Vaccination Starts, by Violet Nabatanzi.

<http://www.newvision.co.ug/news/671498-mass-hepatitis-b-vaccinations-starts.html> [Last accessed 29/09/2015]

therefore timely. Much of this global health attention has occurred and is developing following the period of fieldwork that this chapter is based on. It serves to highlight the way that the international system engages in public health issues within particular frameworks, as will be the focus of the following concluding chapter.

7. THE NEGLECTED TROPICAL DISEASES PARADIGM

“In fact, these are the neglected diseases now, hepatitis and buruli.”¹⁴⁰

On one of my final few days in Adjumani, I was discussing the research findings with a hospital doctor. Having summarised the outcomes from the parasitological survey, I explained that we also had many discussions with people along the river about two other diseases aside from schistosomiasis: hepatitis B and Buruli ulcer. His response above echoed the research experiences. However, from the perspective of people along the river who I had spent time with over the year, *Buruli* was not perceived as neglected in the same way that hepatitis had been. Likewise, it did not seem to be perceived as a threat, unlike hepatitis. In the process of the fieldwork, these findings challenged the construct of *neglected tropical diseases*, and this final point made by the doctor reiterated this. The local realities of the global health concept of neglected tropical diseases did not fit neatly into this categorisation. In fact, they were often far removed.

The realities of neglected tropical diseases and what this meant differed from a global health perspective, a local public health perspective¹⁴¹ and from the perspective of people who are vulnerable to these diseases. These realities were more diverse than the framing in global health allowed. Similarly, the everyday of life along the river was diverse and dynamic, on the one hand illustrating neglect and marginalisation, while on the other hand people found ways to defy these notions.

¹⁴⁰ Discussion, 18.07.2014.

¹⁴¹ I use the term public health here to denote population health concerns (as opposed to individual health concerns), by district and health staff.

In this concluding chapter, I summarise the key findings from this exploration of local realities of neglected tropical diseases. The research and this thesis were framed by an interdisciplinary approach and an exploration of the local context of global public health issues. The analysis presented in this chapter is on the observed divergences between global health and local realities. While the thesis has focussed on three biomedical diseases, the responses to these diseases (from global health policy, through the public health system, and by those living along the river) involved diverse ways of understanding and managing the illnesses.

The overall findings firstly reflect an emphasis on structural determinants of health rather than on biological determinants of disease alone. Secondly, neglect by biomedicine does not necessarily reflect an absence of healing and healthcare options. The absence of biomedicine has produced different social responses depending on historical and contemporary social experiences of health, illness and healing. Thirdly, the paradigm of neglected tropical diseases, while highlighting the social, economic and political context of people who suffer adversely from these diseases, seeks to address this through a biomedical framework. This framework revisits forms of selective primary healthcare without addressing the politics of poverty that ultimately underline these diseases of poverty.

The context of neglected diseases and the conduct of research on neglected diseases, by focussing predominantly on the biological, sets aside these complex issues of local and global politics that shape people's experiences, understandings of, and responses towards health and illness. While there has been increasing attention to the group of neglected tropical diseases, and in particular more recently intestinal helminths, these debates exemplify the abstraction of the biosocial context, of local forms of knowledge and resistance to power.

In this chapter, I begin by summarising the findings. I then discuss the role of evidence in global health and how this has been exemplified through debates in scientific journals and public media on mass drug administration for intestinal helminths. These debates raise a number of points on evidence and analysis in global health and development, as well as interdisciplinary entanglements that have emerged in this field. Reflecting on my own experiences and the findings from this research on schistosomiasis more specifically, I demonstrate that the evidence-making process in epidemiology is inherently a social process that is put aside in these contemporary disciplinary bound debates. Likewise, the success of the role of mass drug administration in controlling schistosomiasis in this area is a part of a biosocial process.

Following this, by reflecting on global health and local realities, I discuss the role of evidence in local health. I look at how empirics and experiential knowledge have influenced people's management of *bilharzia*, *Buruli*, and hepatitis B. Contrasting the diseases demonstrates this inherently biosocial process.

I conclude the chapter and thesis by reflecting on the paradigm of *neglected tropical diseases* in global health. My main argument is that while it has been influential in raising the profile of these otherwise overlooked diseases, it is in itself misleading. What therefore continue to be overlooked are the deep-rooted inequalities and inequities in health, disease and healthcare that are not addressed by shifting paradigms of threats, be they high profile biosecurity threats or everyday threats on socio-economic development. These aspects continue to be side-lined by the gaze in global health framing problems and solutions in particular ways. Significantly, had it not been an interdisciplinary biosocial enquiry, many of the findings in this thesis would have been overlooked by a restrictive disciplinary approach.

NEGLECTED POPULATIONS AND NEGLECTED DISEASES

As discussed in the introduction, the WHO website reports that some diseases are called neglected because they affect disenfranchised populations, persisting in poverty among people with little political voice; people neglected by public health priorities.

Life along the River Nile in the borderland districts of Moyo and Adjumani has long been associated with social upheaval with decades of conflict, and geographical, economic or political marginality. Fisherfolk in particular are vulnerable to a number of the neglected tropical diseases because of the environment that they live and work in, their itinerant lifestyle and their often marginal existence with limited access to biomedical healthcare. Therefore, fisherfolk in northwestern Uganda are an example of what in global health terms would be a neglected population that is vulnerable to neglected tropical diseases.

Yet as this thesis and previous anthropological research (for example Allen, 1992; Allen & Storm, 2012; Allen & Reid, 2015) has explored, everyday life along the river is also associated with resilience and strategies to make sense of outside threats of conflict or threats from within of witchcraft, as well as threats of disease and illness. People have not been passive victims of neglect, marginalisation and disease. Neither have they been passive recipients of biomedical healthcare nor passive onlookers of the absence of biomedical healthcare.

As discussed in chapter three on life along the river, people are challenging historical and contemporary neglect alongside their everyday needs of making a living. While fishers are sometimes viewed as hard to govern, resisting power and authority, they are also eking out a living despite the absence or presence of forms of power and authority. Those living and working along the river have found ways

to carve out spaces to achieve autonomy and agency where other means have left them aside. Local forms of moral authority still play a part in governing life in the villages and landing sites along the river. There are ebbs and flows of the role of formal institutions and authorities (such as fisheries and health) in their life and livelihoods, and with this a reciprocal demand on these authorities particularly when they are then absent. People's trust in these authorities and institutions however, is only further undermined by perceptions and experiences of inconsistencies.

In this context, threats of disease and illness have continued, emerged or diminished. This does not necessarily overlap with global health priorities in the same way. The situation that was found during fieldwork was that the perceptions of threats of *bilharzia* and *buruli* have largely been contained through biomedicine and local medicine respectively. However, the new threat of hepatitis B has emerged as a sequel to HIV/AIDS, and, at least during the time of this study, so far this has been without the biomedical response that has occurred for HIV/AIDS.

While I had begun the study focussing on schistosomiasis, now a relatively widely discussed, researched and known about neglected tropical disease, it became clearer after the survey that this didn't appear to be the affliction that it had once been along the River Nile in this area, at least among adults. In fact one district official reported, '*these are diseases of behaviour now*', reflecting on people's responses to the free distribution of drugs and towards water and sanitation practices. Schistosomiasis is still causing complications elsewhere in Adjumani district and in particular in areas where mass drug administration of praziquantel has not taken place. On first glance this seems to support the distribution of free drugs. Investigating the context of schistosomiasis transmission and the drug distribution among these fisherfolk further however, raises more interesting

questions on why it is that this public health programme has worked in this area and not others. I argue that the answer lies in the biosocial context of the public health programme and the disease transmission cycle.

By spending time with people who are, by the given defining elements, vulnerable to neglected tropical diseases it became apparent that schistosomiasis, which had received biomedical attention was relatively controlled. On the other hand, Buruli ulcer was a neglected tropical disease that received very little biomedical attention in this area. For the hospital doctor, this was a neglected disease with little biomedical treatment available. However, for people living along the river, rather than a threat, nodules and ulcers understood as *Buruli* were largely managed by local herbalists alongside other afflictions such as forms of local poisoning. This continued without raising questions on the absence of biomedicine. Rather than being an emerging public health concern as it is from the biomedical and global health perspectives, it was well-known and a largely manageable condition.

This was in contrast to hepatitis B, which from a biomedical perspective is a well-known disease with a public health intervention to control the disease (through targeted or widespread vaccination programmes). Yet this silent disease, this silent epidemic had become an emerging threat for people in Moyo and Adjumani districts. Alongside this, until very recently, there had arguably been a relative silence from within the geopolitics of global health. Ironically, this was the neglected disease for people along the river and people working in the local healthcare system.

The framing of neglected tropical diseases has arguably side-lined other public health concerns in the districts, in this case hepatitis B. For Buruli, which comes under the paradigm, the framing of neglected tropical disease has not had much

influence biomedically. On the other hand, for schistosomiasis the framing has meant it is no longer neglected. Schistosomiasis has been receiving increased attention in global health, within academia, research, policy and in the popular media. I will return to the paradigm of neglected tropical diseases at the end of the chapter. First I discuss this not so neglected debate; a debate largely about evidence, driven by disciplinary boundaries and norms.

EVIDENCE AND DEBATE

““Knowledge” is not characterizable as difference: indeed, the same or similar knowledge is obviously used and reproduced in different local populations to provide grounds for their thoughts and actions. But there are also divergent bodies of knowledge and different ways of knowing within populations as well as between them.” Barth (1995, p.66)

Among biomedical institutions, knowledge is used and reproduced ‘to provide grounds for their thoughts and actions’ illustrated through contemporary debates surrounding deworming programmes.

Since carrying out this study, there has been a public debate on Twitter¹⁴² and in the International Journal of Epidemiology (Hicks et al 2015; Aiken et al 2015; Davey et al., 2015; Hargreaves et al., 2015; Garner, Taylor-Robinson & Sachdev 2015) on the evidence behind deworming strategies, or mass drug administration, in primary schools. This is in fact a debate that has emerged and re-emerged at different points over the previous two decades, but it has received greater media and social media attention this time around.

¹⁴² #wormwars

As discussed in the introductory chapter, previous Cochrane meta-analyses (Taylor-Robinson, Jones & Garner, 2007) had not found sufficient evidence to support the deworming programme (although this does not necessarily mean that the evidence is against deworming programmes) (Taylor-Robinson, Jones & Garner, 2007). While this method has strict inclusion and exclusion criteria that undoubtedly leaves aside other forms of evidence, it is the gold standard within the field of biomedicine and evidence-based medicine. Therefore, it is quite striking that it has not informed global health policy more strongly. These previous debates on deworming evidence have occurred within biomedical norms surrounding evidence in the form of meta-analyses.

The contemporary debate however, dubbed ‘wormwars’ on Twitter, surrounds epidemiological and economic analyses. The debate revolves essentially around the evidence on the additional benefits of mass drug distribution in schools beyond the treatment of infection – that is, that it has positive benefits on school attendance both within the schools that are treated and within schools that are not treated but are situated within a certain distance from treated schools. The initial study was conducted in 1998/1999 in Kenya by economists Miguel and Kremer (published 2004). Their analysis, as reported in their article, found that the deworming programme reduced school absenteeism and displayed positive externalities to health and school participation, not just within schools that were treated but also within untreated nearby schools. However, they did not find that this had an impact on overall academic attainment as demonstrated through academic test scores.

A reanalysis of the original data by Aitken et al (2015) and Davey et al (2015) from the London School of Hygiene and Tropical Medicine suggested differing results. They firstly replicated the analysis while correcting for errors (rounding errors and

missing data) and secondly conducted an analysis using statistical methods from an epidemiological perspective rather than an economic perspective. In these reanalyses they found that correcting for the errors supported some of the initial results but not others. In particular, the evidence was not strong for the indirect effects of the deworming programme in non-treated schools. In the re-analysis using different statistical replications they raised concerns over the risk of bias in the results due to the data collected, which appeared to differ between treated and untreated schools.

Not only has this become a debate over evidence, but a debate between different forms of statistical analysis between economists and epidemiologists working in the multi-disciplinary field of global health. Each pursues their own disciplinary direction of analyses. This highlights discrepancies between looking at the same data in different ways, and even more so, applying rigid principles to real-life settings.

However, public debates on evidence behind the deworming programmes have previously emerged in different forms. As discussed in the introductory chapter, in 2012/2013 Allen and Parker's anthropological findings were challenged by advocates behind the deworming programmes (Molyneux et al, 2012). Parker and Allen (2014) argued that mass drug administration is a form of de-politicised global health and development programmes as put forward by Ferguson (1990), and that evidence that does not support the programme is put aside through cognitive dissonance. They use McGoey's sociology of ignorance (2012) to argue that "ignorance is deployed strategically" (Parker & Allen, 2014, p. 234). They argued that the money and resources behind these interventions have influenced the continuation of these programmes even when they are clearly not working as they set out to. That is, the large finances behind these global health programmes of

mass drug administration incentivise strategies for ignoring discordant evidence. Their argument highlights the powerful forces that are at play within the landscape of global health.

The features of this global health landscape include not only the large number of actors involved, but within this the donation of drugs by pharmaceutical companies and the large proportion of finances that come from public-private partnerships and philanthropic foundations. Bruun and Aagaard-Hansen (2008) therefore suggested that interventions to manage this have largely been influenced by the availability of free drugs. In doing so, there has been a return to selective primary health care model, which the free distribution of deworming drugs is in effect running as (Allotey et al, 2010; Allen & Parker, 2011).

So what do my findings, as discussed in chapter four on schistosomiasis and mass drug administration, add to these debates? This thesis feeds into the broader debates on evidence-making and approaches to studying and understanding intestinal helminths and the role of the free drug distribution that these debates speak to. However, rather than the disciplinary research that has largely influenced the debates described above, in this study I took a purposefully interdisciplinary, biosocial approach.

Conducting this research highlighted some of the methodological and ethical difficulties in epidemiological evidence-making that lie behind the ideals of evidence-based medicine and evidence-based public health underpinning global health research and policy. Some of these ideals, like sampling techniques and bias, are particularly pertinent for epidemiological evidence purposes and have been part of the critique on the original Miguel and Kremer study that provided support for the distribution. The objectivity that is supposed in evaluating the data that

informs public health policy does not reflect the reality of collecting it, as experienced during this fieldwork.

This study has therefore illustrated some of the difficulties in collecting robust epidemiological data¹⁴³ given the real life settings that it occurs in, settings outside the standards derived from laboratory based randomised controlled trials. In this light, it is not surprising that there are difficulties in the original data collected through Miguel and Kremer's research. The fact that a research programme is running in a school will undoubtedly influence people's responses to attending school, a reality that cannot be controlled for completely. Furthermore, in their study, Miguel and Kremer (2004) raised ethical concerns surrounding testing but not treating intestinal helminths in schools allocated to the control group, therefore pupil's in these schools were not tested. It was not a strict randomised-controlled trial with double blinding; the research process could not be objectified to that degree. On the ground research does not necessarily stand up to the scrutiny of ideals and norms from biomedical evidence-based medicine (Lock and Nguyen, 2010). In this regard, this thesis has demonstrated that a biosocial approach to evidence-making in global health allows for a critical reflection on the methodology and data collection processes which provides a more sensitive (in a non-statistical sense of the word) appreciation of the meanings of the results.

This becomes particularly pertinent when extrapolating the data to inform broader public health policy. The results in the debates on deworming programmes are based on data collected over fifteen years ago in a number of primary schools in Kenya. While the replicability of the initial statistical analysis has been critiqued,

¹⁴³ In discussing the use of the inadequate mortality data by epidemiologists and economists, Kleinman writes that "they serve bureaucratic purposes of the state and the international community" (Kleinman, 1997, p.69).

what of the replicability beyond these primary schools in Kenya? The roll out of mass drug administration across a number of different areas has been analysed by Parker and Allen (Parker et al, 2008; Allen & Parker, 2011; Parker et al, 2012). In their anthropological research on mass drug administration across a number of sites in Tanzania and Uganda, they illustrate the diverse social responses to the programme.

In northwestern Uganda, while the social responses to mass drug administration have been more positive among the Madi, actual uptake remains inconsistent for a number of largely logistical reasons associated with difficulties in the actual distribution of the free drugs. Yet the premise of the mass drug administration programme is based on the uptake of drugs, which it is then assumed will reduce infection levels and morbidity. This is reflected by the monitoring of the programme being largely through drug uptake rather than the more logistically difficult and costly monitoring of infection levels. With this emphasis on drug uptake, epidemiological data is often inadequate. As a consequence, as I have described in chapter four, it is difficult to assess levels of schistosomiasis over time due to inadequate health centre data and limited programmatic monitoring and evaluation of infection levels (which, in line with the global health programme tends to focus on primary school children and not adults).

Despite this, and despite the critiques on mass drug administration, the findings from this study look to support the distribution of praziquantel. This thesis has therefore provided some evidence on the biological response to the programme by demonstrating that there now appears to be low levels of infection among adults at least at the sites surveyed. However, the reasons behind this success are unlikely to be due to mass drug administration alone, but are undoubtedly influenced by other factors related to the local biological, social, economic, political and historical

context. These factors are again largely missing from the contemporary debates surrounding deworming in schools. In investigating the local realities and evidence behind this, as demonstrated in chapter four, if only epidemiological evidence is used we obtain a less than complete understanding of the findings. Grounding this biological evidence in social evidence however produces an understanding beyond the parasitological.

LOCAL EVIDENCE

Beyond the biomedical realm, the findings from this study also speak to the role of evidence in local health: other forms of evidence-making that occur outside the remit of research and biomedicine.

Just like this biomedical knowledge production, local knowledge production and use was based on empirical understandings and experiential knowledge developed over time. This local knowledge drew on historical and contemporary understandings and experiences of illness. It also drew on understandings and experiences of what works or does not work when treating afflictions, whether these are understood to be caused by worms and germs or other forces. These empirical understandings are based on experiences of both biomedicine and local medicine, and as we have seen with schistosomiasis, Buruli and hepatitis B, are not restricted to the biomedical sphere.

For schistosomiasis, mass drug administration had been implemented, even if somewhat inconsistently, for over ten years. Over this time, people reported observed benefits of reducing rates of disease associated with *bilharzia* since the introduction of the free distribution. It was overwhelmingly perceived to have had a positive effect. This response has been situated in broader and sustained legacies

of biomedical healthcare programmes that the Madi have experienced historically (Parker et al, 2012; also see Allen and Storm, 2012).

Such observed and experiential evidence also informed people's healthcare choices in relation to nodules and ulcers associated with Buruli ulcer. Buruli ulcer was a disease that was not wholly or solely addressed through biomedicine. Buruli ulcer, while largely understood to be caused by biomedical entities of germs and worms, was seen as a local disease to be treated by local herbalists, an understanding based on evidence and empirics that informed people's everyday healthcare decisions. However, the treatment largely sought was local treatment, and this does not appear to have changed much despite a more general proliferation of biomedicine¹⁴⁴.

During the period of fieldwork, for people along the river, nodules and ulcers were still predominantly treated by local herbalists, at least initially¹⁴⁵. As a healer, the local herbalist's practice was in part informed by observed symptoms, signs and treatment outcomes. People continued to trust the local herbalist's treatment. A consequence of absent or inconsistent biomedical healthcare as it was experienced by people was that it diminished their trust in it. However, the local herbalists were available and more readily accessible than biomedicine at times.

Like bilharzia, these choices appeared to be largely influenced by experiences of the disease and treatment over time. But unlike schistosomiasis, there had not been a recent public health control intervention. While archival data suggests that ulcers in the early twentieth century were treated as yaws with colonial campaigns in the

¹⁴⁴ The proliferation of biomedicine and medical pluralism in this area is discussed in Allen and Storm 2012.

¹⁴⁵ Different forms of medicine or healing practices merge - a phenomenon that has been termed medical syncretism (Hausmann-Muela et al 2002).

early twentieth century (Vaughan, 1991), in the 1960's published research and accounts suggest that Buruli ulcer was a significant disease in the districts (e.g. Barker, 1972). Accounts from elders recollecting this time suggested that these ulcers had been treated by local herbalists prior to the introduction of biomedicine in the mid-twentieth century for Buruli ulcer. During this time, biomedicine was found to be ineffective at treating the ulcers, and therefore people continued using local herbalist's treatment. While some cases healed, others did not, but the experience that biomedicine also did not cure severe or more advanced cases only served to reinforce the efficacy of local herbalist's treatment.

The longevity of people's experiences of *Buruli* and its treatment was vastly discordant with global health rhetoric on Buruli ulcer that stems from experiences in West Africa. In West Africa, Buruli ulcer has come to attention as an emerging disease and a significant public health concern. It is highly endemic in some West African countries and literature suggests that those affected draw on biomedical and magico-religious understandings of afflictions to explain the disease (Ackumey et al, 2011). My purpose here is not to compare the situation in West Africa to northwestern Uganda, nor to extrapolate discussions on the disease in a highly endemic area to another where the current state of endemicity is largely not known. The contrasting outlooks on the disease are striking however, and it illustrates the divergence between the dominance of one narrative in global health compared to critical reflections on the complexities of these within local biosocial realities.

SILENCE AND NEGLECT

Buruli ulcer has come to global health attention as an emerging disease suggesting that it was not seen prior to this. It had been a concern for colonial doctors during

the 1960's, but the disease has subsequently been re-framed within the neglected tropical diseases and begun to receive greater attention from policy and research from a global health perspective. Yet this is only where the disease is visible. In northwestern Uganda, the disease is largely invisible to biomedicine. It may well be that the prevalence and incidence is low therefore it is rarely seen. But even aside from this, as a disease it is largely not regarded as a disease requiring sole or initial biomedical treatment for the empirical reasons discussed above. In this case, for people who it affects along the river, *Buruli* is not perceived as the threat that it is for global health, despite the fact that it still has serious and severe consequences for some.

The discussions on schistosomiasis, *Buruli* and hepatitis B therefore contrast with each other. As discussed, framed as a neglected tropical disease, schistosomiasis has had a biomedical public health programme implemented with some success and is therefore arguably not so neglected. Chapter five on *Buruli* highlights the discord between the limited biomedical input into the disease and the wealth of local knowledge of the disease. A biomedical approach alone misses these local understandings of disease which have arguably been shaped by this limited biomedical response. However, for hepatitis B, both biomedical knowledge and local knowledge of the disease was limited until recent years. This is further contrasted to schistosomiasis where there has been a local public health translation of a global health response. Yet for hepatitis B, until recently, there had been very little of either. That is, neither a global nor local presence of understanding the disease in the area. There had been experience of liver disease more generally, whether it was understood to be associated with bilharzia, alcohol, intestinal worms, yellow fever or local poisoning. But hepatitis B only emerged as a significant public health concern from 2010 onwards. In this case, people's

understandings of the disease drew largely on their experiences of HIV/AIDS over the previous two to three decades, and to some degree on understandings of witchcraft.

Like *buruli* however, biomedical management of the disease was largely inefficacious or in fact non-existent, but unlike *buruli* there was little alternative apart from to wait and see if somebody had the serious form of the disease or not. Expectations from people's experiences of HIV/AIDS management through biomedical programmes fed into the confusion surrounding the limited testing, treatment and vaccination available for the general adult population at the time for hepatitis B.

There had also been an apparent silence locally that preceded the emergence of the disease as a public health concern. For the WHO the silence in the silent epidemics of hepatitis B in global health comes from a biological silence attributable to the fact that those affected may not know that they have the virus and therefore unwittingly pass it on to others in a variety of ways. For Muraskin (1988), who wrote about hepatitis B in the United States in the 1980's, the silence in the silent epidemic was attributed to a social silence by those who had the power and knowledge to raise their voices including the medical profession and the media. The epidemic in the United States at this time was, similarly to HIV, largely a number of epidemics among high risk groups, such as the medical profession, people who were homosexual, intravenous drug users and the Army. It was not therefore a silence due to a complete unknown but as Muraskin argues, because it was a private public health concern among these groups and particularly among the medical profession who were the ones who could effectively speak out.

In the case of hepatitis B in northwestern Uganda however, why was viral hepatitis not a public health priority prior to 2010? I cannot comment on national or global decision making processes. This research focussed on experiences within the districts, and not within national or global health levels. Additionally, I approached hepatitis B through the lens of neglected tropical diseases. However, from this research I do not think the answer lies in the same social silence that Muraskin wrote about. The medical profession in the districts were unaware of the extent of hepatitis B as a public health problem, and were working within the constraints of the national health system. For the district health office many programmes were implemented depending on global health priorities, such as malaria, HIV and the neglected tropical diseases, with hepatitis B included as part of childhood vaccination schedules. Hepatitis B control was restricted to the Expanded Programme on Immunization.

I also do not think that it solely lies in the biological silence that the WHO wrote of, although this does impact on people's experiences of the epidemic. I would suggest that the silence has come from within the politics of global health, a structural silence, whereby diseases that are framed within global health vie for attention, while others without the same political advocacy are displaced. The big three, HIV/AIDS, malaria and tuberculosis have received global health attention, neglected tropical diseases were pitched against this and now receive more global health attention, but hepatitis B has been a disease that was managed through childhood vaccination programmes. Beyond this, in Moyo and Adjumani districts it was something that came under the remit of the public health system, which was without any means to test, vaccinate (except for children through the childhood immunisation programme) or treat.

Published epidemiological research on hepatitis B suggests that the virus disproportionately affects people in poverty, in rural areas of northern Uganda including northwestern Uganda (Bwogi et al 2005). There are internal factors that are likely attributable to this, with historical legacies that annexed the northern regions of the country, and the more recent conflicts within and around the region. In these respects, hepatitis B is, somewhat surprisingly, arguably an emerging, neglected disease. It affects people in poor, rural areas, and it has been neglected as a public health priority. The situation of hepatitis B in northwestern Uganda fits into the narrative put forward in global health as to why some diseases are called neglected.

This therefore demonstrates that the underlying factors of *neglected tropical diseases* are neither necessarily due to the fact that they are tropical diseases, nor that they necessarily function solely in the tropics. It therefore calls into question the concept of *neglected tropical diseases*.

THE NEGLECTED TROPICAL DISEASES PARADIGM

Neglected tropical diseases are largely defined by the poverty, neglect and marginalisation of those they affect. People living in poverty are adversely affected by the inequitable distribution of disease and poor health outcomes, inequities that extend beyond the group of neglected tropical diseases to public health more generally.

The term *neglected tropical disease* came about as part of a successful lobbying campaign to highlight the neglect of these diseases in global health policy, research and development. The paradigm has had to compete with paradigms of 'biosecurity' and threats to developed nations that emerge from globalisation. The

group of neglected tropical diseases have therefore been juxtaposed to this global security framework as a socio-economic, human development concern.

The diseases were grouped together under the rubric of neglected tropical diseases in order to call attention to the diseases and to call for action. While it has had some effect in naming and framing the diseases in this way, how does the term function? *Neglected* calls for political action. *Disease* calls for biomedical action. *Tropical* suggests an inevitability that these diseases occur because they are situated in a particular geographical area of the globe or climate. Just as global health is a way for developed countries to imagine health concerns in less developed countries (Greene et al 2013). *Neglected tropical diseases* are arguably a way for the global north to speak about diseases that typically occur elsewhere and that pose little threat to themselves. It was predominantly institutions in the global north calling for and implementing action to address these diseases.

However, it is important to note that these diseases have not inevitably occurred in the tropics. Some diseases have been and are prevalent elsewhere. There are many examples, such as hookworm in the United States (Brown, 1976), leprosy in Europe (Cochrane, 1928), and leishmaniasis in the Mediterranean (Ozbel et al, 1995). It is therefore not the geographical, climatic tropics that underline these diseases, although arguably for some this is more relevant¹⁴⁶. Even within countries in the tropics, it is not the fact of being in this global geographical position that causes disease. Within countries, those that are disproportionately affected by neglected tropical diseases are disproportionately affected for other reasons, for social, economic and political reasons that go beyond the fact that the countries are situated in a particular global geographical zone. In a similar vein, Broadbent (2010,

¹⁴⁶ For instance, diseases that require a particular vector, such as a species of mosquito, that is currently only found in tropical climates.

p.52) defines neglected diseases rather than neglected *tropical* diseases. The term tropical is arguably not a defining feature, rather an observational pattern that areas associated with neglected tropical diseases are typically low and low-middle income countries and the highest burden of disease is in sub-Saharan Africa.

Two other points are noteworthy in relation to this. Firstly, in areas where people are affected by neglected tropical diseases, other diseases like hepatitis B also disproportionately affect people. Secondly, the disproportionate effects of diseases like hepatitis B are also not restricted to countries in tropical regions of the world. Dean and Fenton (2010, p.1), echoing the WHO social determinants of health, explain with regards to HIV, viral hepatitis, sexually transmitted diseases and tuberculosis in the United States and globally: "Many of these conditions arise because of the circumstances in which people grow, live, work, socialize, and form relationships, and because of the systems put in place to deal with illness, all of which are, in turn, shaped by political, social, and economic forces." In the United States for instance, health disparities in viral hepatitis, like the other diseases mentioned above, are found among marginalised people, minority groups, young people, females and those in prisons and other institutions (Beltran et al 2011, p.42). This is echoed by other authors on social, economic and political determinants of health and inequities in health and development. Sen (1999) has gone further in pointing out the disparities in health between poor people in rich countries to the rich in poor countries.

As demonstrated, while not a disease confined to the tropics, hepatitis is a disease that has arguably been neglected and disproportionately affects particular segments of a population whether rural people in northern districts of Uganda or elsewhere. This suggests something far more structural than global geographical placing. These diseases disproportionately affect people such as those living in

rural areas in northern districts of Uganda, an inequity in health arising from factors beyond biology and geography.

This argument behind neglected tropical diseases is framed within a rights-based framework, within global health as social justice (Rawls, 2009). One of the original focusses of the definition of neglected tropical diseases was that they affected neglected people who are marginalised with little political voice. Yet within this, as this thesis has attempted to demonstrate, people are exerting agency. They are not just passive victims of unequal distributions of power and resources. Those living and working along the River Nile are finding space to challenge these inequities, be it through political power to bring an ambulance to Obongi County, or in the everyday of making a living along the river. In doing so, where biomedicine has not proved efficacious, for illnesses, like *Buruli*, other forms of healthcare exist. However, while there is an alternative to biomedicine for *buruli* which is perceived to be efficacious in the majority of cases, for hepatitis, where there is also little alternative for fulminant forms of the disease, it is seen and felt as an inadequacy of biomedicine and local biomedical institutions.

For people in Moyo and Adjumani, these biomedical institutions were situated within a globalised world. This was largely from their experiences of international humanitarian organisations and health programmes operating both in the districts and while they were living as refugees in southern Sudan, and also from understandings of development and modernity. Within the socio-political context they were also intrinsically linked to social justice and fairness. As one elderly man explained to me in English during a discussion at a landing site:

“Certain sicknesses can’t be treated here, but are treated in India. When you are a citizen from [here], you suffer the same, but can’t be treated in India,

but those working for the government, who have the money anyway, are taken to India and survive. Those poor here are not supported. Such facilities should also be extended to any citizen regardless, for we are all useful to the government.” [18.02.2014]

As this quote illustrates, health, disease and biomedical healthcare were linked to modernity and citizenship (Allen and Storm, 2012), to a sense of belonging both nationally and within a globalising world. Linkages between global and local spheres of knowledge existed but did not always connect. The injustices were felt when people did not have access to biomedical testing or treatment.

This echoes structural violence, as Paul Farmer has used the term, denoting the politics and violence of suffering, distributed among the poor and powerless from the rich and powerful. However, it goes beyond the nation state’s involvement, to the globalised field of global health. The coining of the term neglected tropical diseases was in one sense a way to give voice to the politically powerless people who suffer from these diseases that had been overlooked by the distribution of power and resources globally and overlooked by global institutions in the face of other high profile public health concerns. However, the solution has been to attempt to redistribute this through biomedicine delivered through a form of selective primary healthcare, without addressing the politics of poverty. In the meantime, people who are vulnerable to suffering from these diseases continue to suffer from the unequal structural distribution of health, disease and healthcare. Neglected diseases in northwestern Uganda, although not necessarily as violent or fatal as the political violence behind HIV/AIDS suffering in Haiti (Farmer, 1996) are still significant issues arising from inequities in health among people living in poor and marginal areas.

Yet while biomedicine is a tool to alleviate suffering inflicted by the politics and violence of structural violence, as has been shown in this thesis, the lack of biomedicine does not mean a lack of healing or healthcare. Whether treating germs and worms or afflictions understood as caused by other forces, other forms of social and individual healing exist which are informed by experiential knowledge. In Moyo and Adjumani, violent forms of social healing have been described by Allen in the 1980's and 1990's in response to unexplained sickness and death in the aftermath of protracted and recent violence and social upheaval. Witchcraft and local poisoning were, and still are, explanations that are drawn on, with or without the presence or use of biomedical healthcare.

For biomedically explained problems, in some cases there were other forms of healing which filled the absence of biomedicine, but in other cases this absence was only revealed further. For *buruli*, local knowledge filled gaps where there was limited biomedical testing and treatment. For schistosomiasis, biomedical treatment had been provided through the free distribution, but testing was still limited. However, for hepatitis B, the absence of biomedicine was accentuated and prominently felt. The structural suffering from biomedical neglect was perceived for hepatitis B, but not *Buruli* and other forms of ulcer. Solely thinking of neglected tropical diseases as diseases which have been neglected by global biomedical institutions detracts from these other forms of healthcare and healing processes. If a sole biomedical view had been taken, *buruli* would have remained concealed. This is not to reify the local or 'traditional' over modern biomedicine, or vice versa. Rather, it illuminates the social processes behind healing and healthcare, which a strictly biomedical view disregards.

In exploring people's everyday experiences of suffering, healing and healthcare, this research has questioned the paradigm of neglected tropical diseases. The first

neglected tropical disease discussed was schistosomiasis, which is now arguably not so neglected and infection levels appear to have reduced among adults along the River Nile. The second neglected tropical disease discussed was Buruli ulcer. Nodules and ulcers associated with Buruli ulcer, have been neglected by biomedicine and Buruli ulcer is experienced as a neglected tropical disease for district health staff. However, for those it affects along the River Nile it is experienced as a well-known condition with treatment available through local herbalists (with or without adjunctive biomedical treatment). The final disease discussed was hepatitis B, not a neglected tropical disease, but one that has arguably been neglected and is experienced as such from both the biomedical healthcare perspective and the perspective of those living along the river.

The realities of these diseases, framed or not framed within global health, subvert the paradigm of neglected tropical diseases. My final point is that while neglected tropical diseases were framed around common features of poverty, neglect and marginalisation, issues that do not solely relate to the seventeen diseases named, but additionally to other diseases affecting people in this context, the solutions have revisited forms of selective primary healthcare. The politics of poverty that underline the inequitable distribution of health are not addressed.

FINAL THOUGHTS

Grouping these diseases together within the paradigm of neglected tropical diseases has led to increased global health attention towards these diseases. This has achieved increased funding, research and attention to the group and some of the individual diseases in particular.

The field of global health has emerged within a landscape of multiple geo-political actors. With this, increased amounts of donations of finances for research and

pharmaceuticals for control programmes have materialised. Some of these diseases are now arguably not so neglected and there have even been successes in controlling some diseases. Yet despite it being a highly politicised term, the outcomes from this lobbying are de-politicised technical fixes (Parker & Allen, 2014).

As a form of selective primary healthcare, mass drug administration for schistosomiasis has likely had some effect in northwestern Uganda along the River Nile; this can only be seen as a success within the biosocial context in which it was applied. In contrast, while *buruli* was largely managed outside biomedical healthcare, the story of hepatitis B highlights the structural neglect of biomedical healthcare. This thesis therefore illustrates some of the limitations of framing different diseases or groups of diseases as competing entities in global public health policy, both in disregarding other forms of healing and in disregarding other public health concerns.

Accordingly, the knowledge of local herbalist's and people's trust in them was contrasted to lack of knowledge on hepatitis B and mistrust in biomedical healthcare. I do not mean this as a critique on the local biomedical public health system and those who work within it; rather the opposite. I approach the analysis through the lens of myopic vision in global health paradigms. Therefore, I see the paucity of knowledge and mistrust in biomedical healthcare as a consequence of broader structural constraints, as a consequence of structural violence (Farmer, 1996). Health care that people can access and where trained staff, diagnostics and medicines are available, is still a predominant necessity. Not only for equity in access, but additionally for building trust in the healthcare system through enabling knowledge to be acquired about health and disease in an area, as opposed to controlling one infection through a specific programme while allowing another to

silently continue. Yet, this needs to be situated within an understanding of local knowledge surrounding health, illness and healthcare.

In exploring the lived realities of neglected diseases this thesis has contributed to literature and research in the field of global health in three main ways.

Firstly, methodologically it has contributed to interdisciplinary work in global health, attempting to break from restrictive disciplinary boundaries. In doing so, I have reflected on the social process of medical research, as an interdisciplinary researcher and for those participating in the research. This illuminated both sites of tension and productiveness in taking an interdisciplinary approach. Significantly, without embedding the biomedical in the social, interpretations of epidemiological data are misleading (such as in explaining low levels of schistosomiasis infection), interpretations of healthcare processes are misjudged (as with Buruli ulcer), and interpretations of what is of public health concern are misguided (as with 'non-neglected tropical diseases' like hepatitis).

Secondly, therefore, empirically this thesis has presented an account of the local realities of global health priorities. It was not possible to carry out similar epidemiological studies within the ethnography for all the diseases considered in this thesis, however the findings are still pertinent to the discussion on local realities of the neglected tropical diseases concept.

While there are limitations on the epidemiological methods used, for schistosomiasis and mass drug administration I have provided empirical evidence on the biosocial context of transmission and control. I have demonstrated that while mass drug administration is likely to have had an impact, the low levels of infection seen among fisherfolk in this area are unlikely to be due to the free

distribution alone, but rather the distribution occurring within a particular biosocial context.

This biosocial approach to understanding global health priorities also allowed for an exploration of the local realities of neglected tropical diseases going beyond a restrictive enquiry on one of these diseases. As this thesis has demonstrated, people vulnerable to neglected tropical diseases are also vulnerable to being disproportionately affected by other diseases for reasons that go beyond the neglect of particular tropical diseases, towards a structural neglect. Within the geopolitical landscape of global health, the problem of diseases of poverty is managed through a selective primary healthcare model, a solution that doesn't address the politics of this poverty.

Thirdly, this thesis has contributed theoretically to literature on global health and neglected tropical diseases. As an empirical piece of work based on understanding local realities, I have not analysed the geopolitics behind global health priorities and within global health institutions, rather I have critically reflected on the local realities of the global health concept, *neglected tropical diseases*. I argue that this framing, while illuminating certain disease priorities, disregards the biosocial context of diseases, other public health concerns and other forms of healing.

Schistosomiasis, a neglected tropical disease, is arguably not so neglected now. A public health intervention has been implemented and this research documents low levels of infection. Yet Buruli ulcer, described in global health as an emerging, neglected tropical disease, was neither emerging nor neglected for people along the river. Although it remains a neglected disease for biomedical healthcare with an absence of biomedicine, conditions understood as Buruli ulcer have been and continue to be largely treated by local herbalists. On the other hand, hepatitis B,

which is not a neglected tropical disease, has emerged as a public health concern. I suggest this is through the same neglect that has been attributed to neglected tropical diseases.

Finally, therefore, I want to caution on framing the diseases as the problem. Neglected diseases emerge, thrive and continue because of structural neglect and silence. People are vulnerable to adverse outcomes from these structural blind spots due to biological, social, economic and political vulnerabilities. Meanwhile, people living and working along the river who shared their time and experiences during this fieldwork continue to find space to resist and demonstrate resilience, drawing on their contemporary and historical social experiences.

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9. APPENDICES

APPENDIX 1, DATA COLLECTION SHEET

Write in or circle appropriate answers when options given

Respondent ID: _____ **Consent given:** _____

Date of interview: _____ **Season of year:** Dry / Rainy

Landing site interviewed at: _____

Background on landing site

Number of inhabitants: _____

Types of housing, e.g. permanent/temporary: _____ Distance from mainland, nearest village/township _____ km

How the landing site is accessed e.g. by road, track, canoe _____ Amenities at the landing site

Number of boreholes: _____ Number of latrines: _____ Fish-cleaning area: Yes/No Fish-processing area: Yes/No Market area: Yes/No

Individual background information:

Sex: Male / Female Age in years: _____

Marital status (single/married/cohabiting/widowed/separated): _____ Number of children: _____

Highest level of formal education: _____ Main occupation: _____ Main place of residence: _____ Ethnic group: _____

Exposure at the landing sites:

Number of years fishing/related occupations: _____ Age of starting fishing/related occupations: ___ Time of day fishing/at the water: _____

Occupation at the landing site (including type of fishing): _____ Occupation at other residence: _____

Main use of the water: _

Time spent in the water/at the water's edge: _____

Movement and mobility:

Type of movement – document Countries, Districts, Landing sites etc. visited including frequency, duration and date (month/year)

Country (Sudan, Congo)	Frequency of visits	Duration of visits	Date (month/year)
District	Frequency of visits	Duration of visits	Date (month/year)
Landing site	Frequency of visits	Duration of visits	Date (month/year)

Length of time spent at current landing site: Days / Weeks / Months / Permanent

Frequency of time spent moving between different landing sites: Daily / Weekly / Monthly / Permanently at landing site

Previous healthcare and treatment used:

Preferred treatment option (provide extra details if given):

Local herbs ____ Local healer __ Biomedicine – private clinics, health centres ____

Treatment actually used for illness/symptoms related to abdominal worms (provide details):

Local herbs ____ Local healer __ Biomedicine – private clinic, health centre _____

Experience of ill health:

Frequency of ill-health experienced (provide details of symptoms/illness):

Most recent experience of seeking healthcare (provide details: when, where, why, what?):

Praziquantel

Total number of times treated: from health centre ____; from MDA ____ Last time treatment taken: ____

Co-artem

Frequency e.g. per month or per year: __ When last treated: ____

Current health concerns or treatment currently being received:

Stool sample result:

APPENDIX 2, INFORMED CONSENT (ENGLISH)

Information and Consent form

Research project: '**Understanding the social drivers of neglected tropical disease: Schistosomiasis and soil-transmitted helminths amongst fisherfolk in north-west Uganda**'

This research project is for a PhD degree at London School of Economics and Political Science, London, with local affiliation with the Social Science Programme MRC/UVRI Research Institute, Entebbe. The research has been approved by London School of Economics Department of International Development and Research Degrees. The research proposal has been reviewed by local Ethics Review Committee in Uganda, the National AIDS/HIV Research Committee (NARC) for Uganda National Council for Science and Technology (UNCST).

The research has been sponsored by a Scholarship from the London School of Economics, UK and a grant from the Parkes Foundation, UK.

The purpose of this study is for research and not the provision of clinical care.

The research is investigating 'neglected tropical disease', e.g. schistosomiasis (bilharzia) and soil-transmitted helminths (Hookworm) amongst people working and living along the River Nile, e.g. fishers. It aims to understand who is most at risk of these diseases and why, and the challenges faced. The research will be carried out over 12 months, from August 2013 until July 2014. A number of landing sites and fishing villages will be visited over this period, and when present, you may be asked to participate in discussions or an interview which may take up to 1 to 2 hours.

You may also be asked to take part in a survey which will involve answering questions about yourself, your occupation, your health and any current or previous episodes of illness. As part of this, you will also be asked if you would be willing to provide a stool sample to have your stool tested for intestinal worms (e.g. bilharzia) by a trained professional using a microscope. If you are found to have intestinal worms, you will be

advised to seek appropriate treatment (praziquantel or mebendazole depending on the infection found) which is free of charge. With your permission, your healthcare provider will be informed of the results. No testing equipment or medication is experimental - they are all standard procedures and treatments. The stool samples will be disposed of after examination and will not be stored.

There are no significant risks or discomfort involved in taking part. However, if you are asked to take part in the stool testing, please inform us if you are pregnant or likely to be pregnant as this will affect the treatment advised which will need to be discussed in more detail with you by the health worker.

If you are found to have another disease or illness that is not under study in this project, you will be advised to seek the appropriate healthcare and referred to the local health centre or hospital.

The results of the research will be written up as a thesis for completion of a PhD. All or part may also be published as an article or book. The results will also be discussed and made available to the Ugandan Ministry of Health, Vector Control Division, and the relevant District Health Officer. It is hoped that this research will contribute to improving public health policy and the delivery of healthcare locally and in other similar settings. It is also hoped that the study will therefore contribute to other research that will reduce the suffering from many of the diseases, e.g. intestinal worms, affecting those living along the major rivers.

All information that you provide will be treated as confidential and anonymity maintained - any identifiable information (e.g. name, address) will be removed when writing up the results.

Your participation is voluntary. If you do not wish to participate you do not have to, and you do not have to give a reason. This will not result in any penalty and it will not affect

your access to health services to which you are normally entitled to. You may also decide to leave the study at any time.

You will not be paid for your participation in the project. It is not anticipated that you will be required to take transport to participate as the study will take place at places of residence or occupation at the landing sites. However, if this situation does arise then you will be reimbursed for the reasonable transport costs.

As a research participant, you will receive feedback on the findings and progress of the study. Any new information that affects the study or data that is of relevance to you as a participant will be made available to yourself or your healthcare provider.

You will be given a chance to discuss the research and your participation in it with the lead researcher, Georgina Pearson, and/or a trained research assistant.

If you have any questions at a later date or would like to discuss the study further please do not hesitate to contact on the details below. A trained translator (speaking Ma'di, Kiswahili or Arabic) will be available promptly to assist as necessary.

In addition, if you have any concerns regarding your rights and welfare in relation to this study please contact: Dr Edward Katongole Mbidde, Chairman National HIV/AIDS Research Committee on telephone number 041-320-631; or the HIV/AIDS Research Committee Secretariat at Uganda National Council for Science and Technology, Kimera Road, Ntinda, on telephone number 041-705-500.

Thank you for your consideration and participation in this research project.

Georgina Pearson

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Informed Consent

To be signed by participant:

The information on this form has been explained to me. I understand the purpose of this study and what my participation may entail.

I understand that I can withdraw from this study at any point, with or without giving a reason, and this will not affect my right to public health care.

I agree to participate in this study (signed)

/ / (date; dd/mm/yyyy)

Thumbprint if unable to sign:

I agree to be contacted for further discussion/interviews (signed)

/ / (date; dd/mm/yyyy)

Thumbprint if unable to sign:

Name of participant:

Contact details: (Village, Parish, mobile number if available)

To be completed by person obtaining consent:

I have explained the above information to the participant who understands the information presented the purpose and nature of the study. They have had the opportunity to ask questions regarding the study (signed); / / (date; dd/mm/yyyy)

Name of person obtaining consent:

Copy of information sheet and informed consent given to participant (please tick)

APPENDIX 3, INFORMED CONSENT (MADI)

Ta Lele Esu Vua Aile Ra Ri Idri

Ta iti undru le lejo lele esu rii idri: **‘Ovi ta di ehwi ni eri jo laza bi bajo laka ku diba idri rii: Obu esule eyi a vua inyaku a ba ebi beka vua oluka meriti ire ewo oru esi itua dere ga ewo Uganda dri ga rii’**

Ta lele esule dii lini nzago adi laka waraga esule tro sukuru nzago inile London aru adi ta la lini dri vua lase dri iga emuki ru ‘Social Science Programme MRC/UVRI Research Institute’ tro. Ta lele esu dii sukuru London dri ria ta ndre di limi dri ewo ta ndredi vu ozo vu ndutu a aile ba adi ubia ca waraga na esujo. Ani dii ba ‘London School of Economics and Political Science’ ai ni. Ta iti undrle lejo lele esu dii ba bale ba lofo Lemu ta ndredi Uganda a, Uganda a ewo ta ndredi urwea ni dri ria Lemu i (National AIDS/HIV Research Committee, NARC), vua Lemu zii ta ndredi dri la kwa obu undrujo baru ritro (Uganda National Council for Science and Technology).

Ta iti undru le dii ba aga na atika ta ehweka sir ii sukuru zii nza ungwele London a ka ta ndre limi dri ide ni zii Parkes Foundation, Ulaya (UK) ri ati aga na ni.

Ta ta dia vu ni undrujo rii idea ta iti undrujo ama adi evu adi ta ti uba laza rua rii ijajo i ku.

Ta ani dii ka ta iti undru laza vu ba ini dri bi bare ga ku diba ti ovidru obu esule eyi andi riia vua obu esule inyaku bani a enzijo enzi rii undrua au. Laza aid ii bena ka ba oluka meri ti vua acika meri a ebi ubeka ri oko au ri i. Ta ti ubale dii ka ba itirile laza di kokoa be vua adusi. Ta iti undrule dii kojia imba ndindi 12 idojjo imba 8 si kinya ani 2013 ndi kofu ca imba 7 dri si kinya 2014. Gonyi ubi vua ei ire gonyi tro riba adi aci laka sir a. Jo vua esu nyi ra ri adi bi nyi zile olobo etuwele lazi zile ria dri ga nosi kodua saa I kusa 2.

Saa ani dru diia adi evu adi nyuzi lazi ekpadru, ovi nya olujo vua ru ebwe vua laza laza ru ta mbajo ri idri. Ta ani dii iti na ka rundru ta ride di ra vua ta andraga ri ni ausi ta ti karuba wa, ama mgbe adi erua kwe tro i ku. Ta okpo rere lejo di iti ni undrujo rii ama mgbe adi erua obu diba dri kwea nyini tro i ku. Adi nyi uzi ta driba nzele nya dri ga, nya ru ebwe ni ga vua

laza nyi koka ra ri idri vua ebu nya idele ri idri, vua satro adi nyi ai kole nya soroni ni adi ipimaa tro laza obu a kwele ikwi kodi au ri ndrejo di nyaia raya ni dri. Jo esuru obu ikwi a diba nya ruga aa ri adi nyi ai kole erua na nyesu, dii kenga nya aire ga. Obu esule eyia diba tia erua (praziquantel mebendazole si) ni hwea tro kenga obu esule nya ruga riba i ilili. Dia vuga kare nya erua esure garii ka ta ni ta iti undrule dii dri ote. Pima soroni dri vua udrwe dri di idea loku loku ta ubi jo ku. Ta ai dii ebu le anda erua jo a riba i, vua jo ipima nya soroni kusa udrwe ni ra naivu adi waa pi omba ta na ku.

Jo ozi nyi ta dii idele, oba nyi lejo a ku hwa. Jo ai nya soroni ni ipima le, jo nyi izi vua nya ru ni anzi kole nyijo ra amala nosi erua eyale kwele nyini rii ka lejo eji nyini ran ni nyijo dakitari ni ra.

Jo ovu esu laza zii nya ruga mgbwi rii au ta iti undru jo dria ru dii ku adi bia nyikonyi le laza dii ijaa ingoa ni itedele nyi ni ra, ku sa erua jo ingo ia ya i.

Lejo esule ta dia iti undrure ga rii ebua waraga lini nzago karatasi zii lini esujo ri ni. Zii adibaa ba kulaa bugu a ausi laza igoga jo wa. Ta esule ta dia iti undrure ga dii kwea gamete Uganda dri dri ewo ru ebwe dri kodi ri dri vua ba ebu ideka ewo logurutumwi kodi ri dri. Itiriru ta esule ta iti undrure ga dii kea ka ba ni lidri ru ebwe dri laki ni lofo ga ri eco ra vua konyi kwele ru ebwe tro ri dri karidu ra ei lofo si i.

Ta nyea nya nzele rii adi usia cici ki oba nya ru ama tadii inze nyi i ni madi zi konia kpe.

Ta ai dii adi nyuzi dria ru lukwe ako kesua adi nyizi nyaia kpa. Jo nyidri ile ku iri ori nyi ku, vua iga lazi diba aika mgbe ni adusi ni ozi nyi ku. Vua aru okwe nyini lamgba sa ku, vua erua esuka isa igoga nyini ku. Nya lazi di aika niga saa ana idojo risi kusa adi idoa nyi uzile kpa sa wa. oca lazi idore zile nyidri ku madi eyadi lazi uzidi ri ka nya ra ni zi kpa.

Evu uhwe nyi ku lazi diba aire ga i, vua itiri ra nyebu okolongo ai ni sa ku amala ba kevu nyidri esi, jo esuru nyiya nyi i adi nyi ni lovu angwa gaadru ri hwe ra.

Jo ta iti dii undru ru ra, ai na esu le rii adi evu adi dri ba na nzea nyini ra. Ta anyi elo di rii sa nya uzi ka ra si adi driba na nzea anyini ra vua dakitaria anyi ilofu rii sa konia ote.

Madi ani dii kolu zaangwa Georgina Pearson i kusa madi zi ani ikonyi di ta dia iti ni undrure ga ri i.

Jo lazi zii nyini zile aa ata kolu vule ga odu zisi ku sa nyea nyizia wa, madi ru sile lile ledi i vua ana toiloru a namba isa aa lile ledi i. Madi ta driba nzedi anyini madi tisi kusa Kiswahili si nosi Arabic si rii Kolu anya lofo ga aa.

Ta inzajo, jo nyini lazi zii zile aa anya olu ni dri ta dia iti ni undrure gasi, oriku nyizi Dr. Edward Katangole Mbidde ni Komi dipi ta ndredi ewo urwea nia lemu ni dri rii au, ana toiloru namba ni 041-320-631 Kusa madi ta usidi lemu Uganda dri ta ndredi ewo dri lakwa driiga ri au ani Kolu leti Kimera dri riiga Ntinda ana toiloru a namba ni 041-705-500.

Manzo okpo si nya saa duka lazi diba ti aika si vua nya aika ta iti di kundruru si.

Georgina Pearson

+256 (0) 787-459-261 (mtn)

+256 (0) 793-769-007 (orange)

Ta nyai le ra rii

Madi uzile ria dri tika:

Ta usile waraga dii dri rii onze mani driba na ra. Meri ta iti undrule dia ehwi ni ra, vua ai ma hwele ria ehwi ti tro.

Meri ehwina ra jo ale ni ma ma nze lazi diia si pi ni wa, vua anze ma pi ni adusi ni oziku, oko imba ma konyi esule ru ebwe dri ri iga ku.

Mai ra lazi diba ai jo (mai)

/ / (odu)

Jo ma ta si kpe, ma dri ago ti:

Mai ra ma esujo ma dri ei a kusaa toiloru si namba (mai)

/ / (odu)

Jo ma ta si kpe, ma dri ago ti:

Ru madi lazi aidi ridri i:

Ta madri gar ii: (ei, mukungu, toiloru namba jo aa i)

Ma di lazi uzi di ri kosia ni:

Ta oru sile diba anze drib a ma madi lazi ai di ni ra, oko eri ehwi na ra adi lazi dii uzi adusi ya i. Oko uzi lazi ta iti undrule dia driga ra (mai); / / (odu)

Ru madi lazi uzidi ri dri i:

Karatasi dia erijo rii ta aru ri tro ohwe madi lazi dba aidi ri dri tro (nyi pe ra)

APPENDIX 4, RESULTS: PRAZIQUANTEL AND CO-ARTEM DRUG UPTAKE BY SITE

PRAZIQUANTEL (PZQ) USE BY SITE

SITE 1

PZQ	Male	Female	Total
N	11	22	33
% ever taken from Health Centre	18.18	18.18	18.18
% ever taken from Private clinic	0	0	0
% ever taken from MDA	72.73	86.36	81.82
% taken in preceding year (2013)	36.36	68.18	57.58
% never taken	9.09	4.55	6.06

SITE 2

PZQ	Male	Female	Total
N	25	24	49
% ever taken from Health Centre	8	16.67	12.24
% ever taken from Private clinic	0	0	0
% ever taken from MDA	96	100	97.96
% taken in preceding year (2013)	28	66.67	46.94
% never taken	0	0	0

SITE 3

PZQ	Male	Female	Total
N	10	16	26
% ever taken from Health Centre	0	6.25	3.85
% ever taken from Private clinic	10	6.25	7.69
% ever taken from MDA	80	100	92.31
% taken in preceding year (2013)	20	43.75	34.62
% never taken	0	0	0

SITE 4

PZQ	Male	Female	Total
N	21	8	29
% ever taken from Health Centre	14.29	12.5	13.79
% ever taken from Private clinic	9.52	0	6.9
% ever taken from MDA	85.71	87.5	86.21
% taken in preceding year (2013)	38.1	25	34.48
% never taken	14.29	12.5	13.79

SITE 5

PZQ	Male	Female	Total
N	7	6	13
% ever taken from Health Centre	14.29	33.33	23.08
% ever taken from Private clinic	14.29	0	7.69
% ever taken from MDA	100	83.33	92.31
% taken in preceding year (2013)	42.86	33.33	38.46
% never taken	0	16.67	7.69

SITE 6

PZQ	Male	Female	Total
N	12	11	23
% ever taken from Health Centre	16.67	9.09	13.04
% ever taken from Private clinic	8.33	0	4.35
% ever taken from MDA	100	90.91	95.65
% taken in preceding year (2013)	41.67	36.36	39.13
% never taken	0	0	0

SITE 7

PZQ	Male	Female	Total
N	25	20	45
% ever taken from Health Centre	16	15	15.56
% ever taken from Private clinic	28	5	17.78
% ever taken from MDA	92	95	93.33
% taken in preceeding year (2013)	72	80	75.56
% never taken	4	5	4.44

SITE 8

PZQ	Male	Female	Total
N	17	12	29
% ever taken from Health Centre	35.29	0	20.69
% ever taken from Private clinic	0	0	0
% ever taken from MDA	100	100	100
% taken in preceeding year (2013)	64.71	58.33	62.07
% never taken	0	0	0

SITE 9

PZQ	Male	Female	Total
N	22	16	38
% ever taken from Health Centre	4.55	18.75	10.53
% ever taken from Private clinic	9.09	6.25	7.89
% ever taken from MDA	95.45	81.25	89.47
% taken in preceding year (2013)	77.27	75	76.32
% never taken	4.55	0	2.63

SITE 10

PZQ	Male	Female	Total
N	18	17	35
% ever taken from Health Centre	22.22	5.88	14.29
% ever taken from Private clinic	5.56	0	2.86
% ever taken from MDA	100	88.24	94.29
% taken in preceding year (2013)	55.56	52.94	54.29
% never taken	5.56	0	2.86

SITE 11

PZQ	Male	Female	Total
N	19	15	34
% ever taken from Health Centre	15.79	6.67	11.76
% ever taken from Private clinic	15.79	6.67	11.76
% ever taken from MDA	100	93.33	97.06
% taken in preceding year (2013)	94.74	60	79.41
% never taken	0	6.67	2.94

SITE 12

PZQ	Male	Female	Total
N	15	14	29
% ever taken from Health Centre	26.67	14.29	20.69
% ever taken from Private clinic	13.33	0	6.9
% ever taken from MDA	100	92.86	96.55
% taken in preceding year (2013)	40	42.86	41.38
% never taken	0	7.14	3.45

COARTEM USE BY SITE

SITE 1

Coartem	Male	Female	Total
N	11	22	33
% taken in preceding year	27.27	59.09	48.48
% currently taking	0	0	0
% taken in preceding month	18.18	18.18	18.18
% never taken	54.55	27.27	36.36

SITE 2

Coartem	Male	Female	Total
N	25	24	49
% taken in preceding year	68	91.67	79.59
% currently taking	4	4.17	4.08
% taken in preceding month	12	20.83	16.33
% never taken	28	8.33	18.37

SITE 3

Coartem	Male	Female	Total
N	10	16	26
% taken in preceding year	70	93.75	84.62
% currently taking	0	0	0
% taken in preceding month	10	25	19.23
% never taken	30	0	11.54

SITE 4

Coartem	Male	Female	Total
N	21	8	29
% taken in preceding year	80.95	87.5	82.76
% currently taking	0	0	0
% taken in preceding month	33.33	12.5	27.59
% never taken	19.05	12.5	17.24

SITE 5

Coartem	Male	Female	Total
N	7	6	13
% taken in preceding year	71.43	100	84.62
% currently taking	0	0	0
% taken in preceding month	0	33.33	15.38
% never taken	14.29	0	7.69

SITE 6

Coartem	Male	Female	Total
N	12	11	23
% taken in preceding year	83.33	54.55	69.57
% currently taking	0	0	0
% taken in preceding month	25	0	13.04
% never taken	8.33	27.27	17.39

SITE 7

Coartem	Male	Female	Total
N	25	20	45
% taken in preceding year	60	80	68.89
% currently taking	4	0	2.22
% taken in preceding month	32	25	28.89
% never taken	40	20	31.11

SITE 8

Coartem	Male	Female	Total
N	17	12	29
% taken in preceding year	76.47	91.67	82.76
% currently taking	5.88	0	3.45
% taken in preceding month	17.65	33.33	24.14
% never taken	5.88	0	3.45

SITE 9

Coartem	Male	Female	Total
N	22	16	38
% taken in preceding year	90.91	100	94.74
% currently taking	4.55	0	2.63
% taken in preceding month	22.73	37.5	28.95
% never taken	9.09	0	5.26

SITE 10

Coartem	Male	Female	Total
N	18	17	35
% taken in preceding year	77.78	94.12	85.71
% currently taking	0	5.88	2.86
% taken in preceding month	22.22	35.29	28.57
% never taken	11.11	5.88	8.57

SITE 11

Coartem	Male	Female	Total
N	19	15	34
% taken in preceding year	73.68	100	85.29
% currently taking	0	0	0
% taken in preceding month	10.53	26.67	17.65
% never taken	5.26	0	2.94

SITE 12

Coartem	Male	Female	Total
N	15	14	29
% taken in preceding year	86.67	100	93.1
% currently taking	0	0	0
% taken in preceding month	13.33	21.43	17.24
% never taken	6.67	0	3.45