Firoz Lalji Institute
for Africa

Living the Everyday: Health-seeking at Uganda’s Borders

Summary of Project Findings

Working paper no.3

Elizabeth Storer*[1] (Firoz Lalji Institute for Africa, LSE) and Georgina Pearson (Institute for Global Health and Development, Queen Margaret University, Edinburgh) with Solomon Kamurari (UUKHA), Emmanuel Candia, Innocent Anguyo, Osuta Jimmy, David Angualia, Patricia Nyivuru, Clement Aluma, Anzuvuku Phillip, Francis Sebbi and Moianya Caesar

Living the Everyday: Health-seeking at Uganda's Borders

Acknowledgements

This research was funded through a British Academy Knowledge Frontiers grant (KF3/100195). We acknowledge the participation of collaborating institutions: Firoz Lalji Institute for Africa (FLIA), Gulu University, Muni University and Uganda UK Health Alliance (UUKHA). We thank all research participants in Arua and Moyo for their involvement in the research process.

Research Clearance

Approval for this research was provided through Gulu Unversity REC (UG-REC-017) and UNCST.

Project Team

The Principal Investigator providing oversight for this research is Prof Tim Allen, Director of the Firoz Lalji Institute for Africa, London School of Economics. Co-Investigators are Dr Georgina Pearson, Queen Margaret University, Edinburgh and Prof Grace Akello, University of Gulu. Dr Jimmy Odaga. Dr Elizabeth Storer was a post-doctoral researcher with this project.

Contents

- Introduction
- Research Sites and Methodology
- Key Findings: Arua
- Key Findings: Moyo
- Project Findings
- Implications
- Concluding Remarks
- Project Outputs

The Firoz Lalji Institute for Africa (FLIA) focuses on engagement with Africa through cutting-edge research, teaching and public events, strengthening LSE's long-term commitment to placing Africa at the heart of understandings and debates on global issues.

Foreword

On 21st March, 2020, Uganda confirmed its first case of COVID-19. As across the world, the pandemic has caused enormous health, economic and social impacts across the regions of the country. Whilst the COVID-19 pandemic found a resilient health structure that had been put in place to control similar public health emergencies including Ebola and HIV/AIDS, the magnitude of the disease overwhelmed existing capacity, and severely disrupted other routine health services.

The capacity of the health system in West Nile to react interfaced with long histories of mitigating disease epidemics and outbreaks, as well as meeting to the needs of South Sudanese refugees who require medical care in the region. At present, West Nile is estimated to host over 1.5 million South Sudanese refugees.

Insights in the response to COVID-19 in the West Nile region therefore represents the complexities that health systems in settings with multifaceted demographics and disease burdens faced at the different stages of the pandemic.

The Living the Everyday Project, hosted by the Firoz Lalji Institute for Africa (FLIA) at the London School of Economics & Political Science, together with collaborating Ugandan Institutions has captured important insights through first-hand experiences of health workers and communities that were at the centre of responding to the pandemic.

As a mutual collaboration between the Ministry of Health, Uganda and the UK, The Uganda UK Health Alliance (UUKHA) was pleased to support the institutions involved through the different stages of the study and looks forward to coordinating efforts to translate the findings in policy and practice

The in-depth perspectives captured through intersecting methodologies by the study will therefore significantly contribute to approaches of designing broader response plans for future disease outbreaks in Uganda. The study further built much needed capacity in qualitative research in social determinants of health and health systems among collaborating Ugandan institutions and researchers.

Dr Solomon Kamurari

Head of Programmes,

Uganda UK Health Alliance

Introduction

'Living the everyday' addressed how social relations and everyday life in borderlands affect knowledge and management of sickness, including ‘old’ and ‘emerging’ epidemics. Based in the West Nile sub-region of Uganda, research sites were situated on the Uganda/ Democratic Republic of Congo (DRC) and Uganda/ South Sudan borders. At the time of devising the project, these borders had come to the attention of national and international experts, under the guise of Ebola-preparedness efforts following the spread of the epidemic from North Kivu, DRC. More recently, populations in the research have been affected by COVID-19 prevention measures.

The project sought to understand how epidemic responses affect everyday health-seeking in and across these spaces. Through building on previous research, and collecting new ethnographic data, the research team sought to capture everyday perspectives hidden from rapid assessments which characterised many external attempts to understand Africa epidemics.

The research programme aimed to promote interdisciplinary working, drawing on expertise, approaches and insights from across anthropology, geography and public health. The methodological and analytical approach foregrounded ethnographic research, theory and insights, embedded within this, understandings and insights will be drawn from fields of public health and biomedicine. While there are often-cited disciplinary tensions across social science, humanities and biomedical sciences, the knowledge produced through and disseminated by these fields are pertinent to studies to health and health-seeking, and there is an apparent and increased realisation, or desire, to work across disciplines in response to emerging public health threats. This research is therefore timely in that it seeks to forge cross-disciplinary, and interdisciplinary, working. However, rather than social sciences and humanities as an ‘add on’ component, they are core. And rather than excluding or discounting biomedical norms, these are re-situated and re-contextualised within the everyday life experiences of people living in particular spaces.

The research was located in the West Nile sub-region of Uganda, along the Uganda-Democratic Republic of Congo (DRC) and Uganda-South Sudan borders. An understudied and historically marginalised region, it came under particular scrutiny following the Ebola outbreak in neighbouring North Kivu, DRC in 2018. The Ebola epidemic, and the COVID-19 pandemic, have ongoing implications for West Nile, where there is continual movement of

goods, people and information across borders. Everyday dynamics of these movement are often overlooked in public health policy. Beyond official check-points, the borders are largely unpoliced, and before the 1950s, were mostly not demarcated. Taking a historical perspective, we examined a) how people living directly on an unpoliced and demarcated national border formulate knowledge about the origins, cause and treatment of sicknesses, and b) how borderland locations affect care-seeking choices.

Background Context

The West African Ebola epidemic (2014-15) signalled a commitment to integrating social; science perspectives into the management of epidemic/ pandemic crisis. Indeed, 'local' perspectives were also foregrounded in the public health response to the 2018 Ebola outbreak in the DRC, which was cast as a threat to Western Uganda.

Whilst this integration of qualitative research into disease prevention held promise, it also brought new problematics. Ethnography quickly became equated to "rapid assessments", favoured particular spaces, voices and narratives and privileged epidemics above other health concerns. Much of the 'rapid' research, in response to an emergency situation, featured spatial slippage – it was imprecisely grounded, and located in places many miles from the actual border. Yet, ideas about illness can differ remarkably across urban and rural areas, and within several km of the border.

Research during Ebola outbreaks may have signalled a recognition of the need to understand local context. Yet, throughout Covid-19, anthropological and social science inquiries remained peripheral to the global response. As such, policy responses continued to address disease-specific issues through established mechanisms, premised on narrow and largely a-historical understandings of risk factors and interventions.

This research rests on the premise that there are deep implications of not taking into account longer histories of illness and knowledge, grounded as they are in specific histories of localities. Whilst outsiders (and insiders) have associated population flows as dangerous, questions remain as to how people actually engage with others. We urge ways of talking about distance to be placed into a context of mundane everyday engagement. In Uganda, for example, the international community speak of South Sudanese refugees as a "strain on host communities", while many Ugandans recognise those who live across the border as kin, or as conferring socio-economic opportunity. Similarly, whilst Ugandans may explain that

particular diseases “come from Congo”, this does not mean that responses are not localised, or that Congolese citizens are ostracised.

The above insights on Ebola response bear particular resonance with attention subsequently diverted to COVID-19 preparedness and response, with little time for reflections on one epidemic before moving on to the next. The response to COVID-19 restrictions in West Nile warrant analysis, since opposition to measures was reportedly higher than across wider Uganda. Throughout 2020, fierce resistance to COVID-19 measures – and containment in particular – was reported from many communities across West Nile. In both Arua and Moyo Districts, local resistance (which on occasion became violent), opposed the official designation of quarantine sites for the sick.

In part, this resistance emanated from the disruption to livelihoods posed by Covid-19 restrictions. As some of Uganda’s poorest districts, the implementation of nationwide lockdowns had significant impact on the livelihoods of the sub-region’s traders and agriculturalists. A common refrain which circulated during Lockdown 1 (from March 31st 2020), was whether people in West Nile would die first of hunger, or of COVID-19.

Popular attitudes shifted by early 2021, when the number of Covid-19 deaths increased in the region. Yet, despite an acceptance of the realities of Covid-19, uptake of Covid-19 vaccines has been lower. Whilst this is in part due to supply-side issues, our research captured fears and reluctance to take vaccines.

Given that our research unfolded against this changing backdrop – with interviews occurring between June – December 2021, we offer ethnographic insights as to the textures of resistance and reasons for vaccine ‘hesitancy’. We thus contribute to the global omission of ethnographic research as to the dynamics of Covid-19 and resistance on the ground.

Approach: From the exotic to the everyday

To counter tendencies of rapid, narrowly defined assessments, we move to the everyday. The research is neither limited to rapid assessments, nor individual diseases. Beyond Ebola and COVID-19, this research captures local conceptions regarding sickness including hepatitis B, HIV/AIDS, plague, TB, malaria as well as chronic sicknesses. Alongside cross-border therapy seeking, we also considered the rhythm of everyday movements of goods and people across borders and the implications of these flows.

Foregrounding conceptions, perceptions, and everyday experiences, we take into account that this includes individuals and groups from external organisations (public health practitioners, academics, state officials, journalists) present for periods of time, in response to crises, and longer-term duties. Thus, this research explores the production of, and encounters between, academic, professional and lay knowledge through engagement with people living, working and traversing through the region. By doing so, it draws important insights on the tensions and disparities that arise across different communities of knowledge and practice. Notions of epidemic disease and crisis form just one part of local packages of knowledge.

Three sets of research questions were posed which, in being broad, allowed us to take into account local circumstances.

> The first set of questions related to everyday knowledge production. How do academics, media, public health practitioners and people living on and across borders discern and produce knowledge about illness? How are these conversations affected by the border? How do social and economic relations inform knowledge about sickness, and play out beyond illness belief? How do people conceptualise flows of knowledge, goods and people from beyond the border?
>
> The second set of questions related to everyday health-seeking practices. What informs patterns of therapy-seeking? Do people move across the border to seek therapy, and if so, what forms does this take?
>
> The third set of questions related to the interface between the forms of knowledge and ideas produced by the various people and groups at the border. Where and what are the sites of convergence and divergence between different bodies of knowledge produced on and about border life, health and health-seeking? How do these inform policies and practices in response to contemporary and potential/emergent threats across borders?

Research Sites and Methodology

Research was focused at two border sites, one the Arua-DRC border and the other the Moyo-South Sudan border. These are areas where members of the research team had previously worked for significant periods and had established research relationships. The research was conducted in accordance with contemporary guidelines and restrictions on social

distancing, travel and work. We aimed to capture a variety of perspectives from people in village and urban settings.

COVID-19 had a significant impact on the ability for us to complete the research as originally planned. The closure of research institutions presented obstacles to ethnographic fieldwork, and delays in data collection using adapted methods focusing on in-depth interviews carried out by an experienced, trained Ugandan research team. We thus used feasible intersecting methods: remote semi-structured interviews; documentation of epidemic histories; analysis of participant diaries; and review of archival material, published literature, grey literature and media reports.

Starting with contact with individuals working and living in specific settings, we used a snow-balling technique to recruit further participants. In Moyo, twenty-six in-depth, semi-structured interviews were conducted with key informants (elders, Local Councillors, District Officials, healers and healthcare practitioners), and eleven epidemic life histories were documented with people living in the border region, whereby participants were asked to document their current perspectives and experiences of health messaging and health-seeking. 41 interviews were conducted in Arua town and its vicinity. The sample included health workers (in the community, working at ARRH, as well as in the COVID-19 task force), government officials, teachers, herbalists, pastors, elders, as well as 'ordinary' citizens.

The interviews were conducted to assess contemporary health concerns and reported pathways of health-seeking. This enabled us to first document background demographic characteristics of people living in these border areas, and second assess broader trends in both public health concerns for populations living and working in these areas, and health-seeking pathways. Situating the research in historical context, a structured review of archival material, published literature, grey literature and media reports was conducted to elicit insights on the historical context of the border in relation to the state, disease and control of movement of goods and people. In doing so, we triangulate findings from the interviews, life histories, media and archival review.

Thus, various modes of knowledge production among different groups of people at the border were documented. Academic knowledge was assessed through a review of published articles on the border region, in addition to the research team's cross-disciplinary perspectives. The portrayal of the border region in local and global media was assessed through a review of relevant articles published on Ebola, COVID-19 and other disease threats. Professional knowledge focused on historical and contemporary public health

responses, through a review of archival material, policy documents and briefs. Lay knowledge incorporated perceptions, perspectives and practices of people living across the border region, established through, key informant interviews, semi-/ unstructured interviews and life histories.

An inductive, thematic analysis was conducted manually on the various forms of data collected (interview transcripts, epidemic life histories, archival material and document and media review).

Our findings were validated through an online dissemination workshop ‘Health at Uganda’s Margins: Dissemination Workshop’, which was co-hosted by the Firoz Lalji Institute for Africa, Uganda-UK Health Alliance and Muni University, West Nile. They key findings were presented and extended time given for over 40 stakeholders from the region to respond and shape the central outcomes.

Ethical approval was granted through the London School of Economics and Political Science Research Ethics Committee, and Gulu University Research Ethics Committee (GUREC-2021-43). Research clearance was granted through the Uganda National Council for Science and Technology (UNCST, reference SS878ES).

Key Findings: Arua

41 interviews were conducted in Arua town and its vicinity. The sample included health workers (in the community, working at ARRH, as well as in the COVID-19 task force), government officials, teachers, herbalists, pastors, elders, as well as ‘ordinary’ citizens.

Health Priorities

- When respondents were asked as to the most pressing health priorities in Arua, the majority cited endemic, chronic and occasional illnesses. Malaria was most often cited as the principal health concern. Other illnesses included typhoid, pneumonia, skin-infections, snake bites, dysentery, diarrhoea, malaria, typhoid, cough, headache, ulcers, asthma and reproductive illnesses.

- According to health officers too, the, most pressing priorities in Arua are often not epidemic diseases. Malaria was most often cited as the principal health concern, along with

pneumonia. One Health Worker from Arua Regional Referral hospital clearly elucidated the divergences between funding for epidemics and other health conditions. He explained " *Despite the fact that Uganda has clear 5 minimum health care packages clustered under: 1. Maternal child health, 2. Communicable diseases (epidemics), 3. None communicable diseases, 4. Health promotion and disease prevention and 5. Mental health epidemics preparedness and prevention, not all clusters are given the same attention.*" This respondent went on to explain that the focus on epidemics lead to other priorities being neglected, *"Despite malaria being a leading disease when epidemics like corona emerge, government and communities' tend to shift their attention to such epidemics, posing a threat to other forms of health care"*.

-Respondents indicated that care – and respected advice about how to treat specific ailments - was formed through a blended approach. Parents and elders hold responsibility within homes and clans, with male household heads often having the final say in budgeting for, and approaching care for other household members. Ultimately, it is household heads who have responsibility for the health of families, and clan heads for the health of the clan. Whilst, in reality, approaches to treatment are often flexibly negotiated amongst family members, options reflect the strongly patriarchal nature of Aruan society. This was a finding prominent in Storer's doctoral research, which found that whilst men were more likely to treat chronic conditions in clinics, women often turned to Christian faith healers or diviners. This in part reflected the availability of funding within households: treating men was prioritised, and children after that. Women often turned to free therapies from the church, even for acute conditions.

- When describing how the everyday sicknesses listed above (as well as epidemics) were treated, respondents reported an acceptance of biomedical treatment, often alongside herbal remedies and prayers. Common everyday illness were generally reported to be managed through obtaining drugs for a government or private clinic: malaria was generally treated with Quoartem tablets, diarrhoea with Flyagil tablets, typhoid treated Ciprofloxacin. For other conditions, including skin lesions and ulcers, many reportedly treated with herbal remedies. It is when these symptoms persist that elders, faith healers and diviners are consulted for the root cause (i.e. moral social cause) or sickness. Our respondents confirmed the portraits of healing described by Storer (2020) in Arua and Maracha, and Allen and Storm (2012) in Moyo.

Epidemic Histories

Respondents were asked as to their memories of HIV/AIDS, Ebola and COVID-19, these being the epidemics which have received international attention. Questions aimed to gauge: understanding of these three epidemics; how Aruans became aware of new “threats” and how these threats related to local priorities.

Both citizens and health workers effectively differentiated between transmission of HIV/AIDS, Ebola and COVID-19. Despite understanding these diseases as distinct, continuities emerged in how the diseases were understood:

- Often, the signs of these diseases were differentiated by the nature of their transmission, or the visible effects diseases had on the body. For example, one interlocutor explained: “ Ebola blood comes out through all openings of the body, Covid-19 is got when close to one another, HIV is sexually transmitted”
- All epidemic threats were understood as external to the region, brought into the population in West Nile by people coming into the sub-region. Often, diseases were said to be brought by non-residents who had trading connections with the region, and so regularly (or informally) crossed district, or international borders.
- Whilst the distinct and symptomatic nature of each epidemic threat was noted, in each case there was a lag time between health information being administered, and local evidence supporting which fostered widespread acceptance of explanations. This was particularly observable in HIV/AIDS, Hepatitis-B and Covid-19. It took several years before the disease – and its management – was incorporated into local therapy pathways. Trust in biomedicine was often evidence when people survived cases of diseases locally.
- Even with reference to memories of suffering during the first decade of the HIV/AIDS pandemic, and the recycling of vernaculars of HIV/AIDS in subsequent pandemic, the Covid-19 response was understood as unprecedented. This was because viral restrictions affected livelihoods in ways which disease control during HIV/AIDS, Hepatitis-B and Ebola (which failed to manifest), did not.

HIV/AIDS

HIV/AIDS which was initially known as 'silimo' (as in Southern and Central Uganda), because of the mass wasting associated with the disease. Its arrival is attributed to the activities of the Tanzanian army who accompanied the troops of Obote II into the "liberation" of the region following the ousting of Idi Amin in 1979. Transmission is associated with rapes enacted by troops, as well as through commercial sex with the foreign soldiers during that period of the fighting. Whilst this transmission narrative has been debunked (Allen 2006), it still holds explanatory power as an HIV-origin myth in the region. It is indicative in part of the temporality of the pandemic, which arrived in the region in the decade following return from exile out of Uganda, into the Democratic Republic of Congo and South Sudan.

HIV/AIDS is now widely understood by Aruans to be 'transmitted in the blood' or through 'sexual intercourse'. Understandings of the virus were widely attributed to have change following the arrival of ARVs in the district from the early 2000s, through which disease outcomes shifted from dying, to surviving and living with HIV. As such, HIV/AIDS is managed through biomedicine – often explained as being administered by the "government", rather than herbal medicines.

Respondents had clear memories of the evolution of the HIV/AIDS public health response, entangled as these were with memories of post-war leadership in the region. Many recanted the messages of the time, which linked disease prevention to moral restraint. One interlocutor explained that strong political leadership resulted in the transmission of messages of "abstain from sex, stay with one marriage couple, and use condoms if you cannot avoid sex". Whilst therapy is often administered by a meshwork of NGOs, its treatment is strongly associated with the NRM government in Arua.

Ebola

Ebola is largely understood with reference to bleeding from bodily orifices. For example, the infection was described as accompanied by "bleeding through the nose, mouth, ears and even private parts", or "in Ebola, blood comes out through all openings of the body." Health workers explained the virus was often accompanied by a high fever, headache and anaemia. It was understood that the "victim dies within short period of time, like two days."

Ebola was widely said to be brought from Congo and was often linked to consumption habits: "monkeys lived there, but when the community that lived in the same area started eating the monkeys, they ended up contracting the disease that now spread to Uganda being at the border with Congo." In addition, there was fear that due to poor health services in

Congo, people suffering from Ebola may seek assistance from health services in Uganda. This was the cause given for the Ebola outbreak in Gulu in 2000 (there was more focus on this epidemic than on later outbreaks).

Despite the significant resource that was plied into Ebola prevention efforts following the epidemic in Eastern DRC during 2018-19, no interlocutors had direct experience of witnessing, or managing an Ebola case. Thus, whilst people had knowledge of the transmission, and often repeated verbatim public health messages, Ebola was often described as a distant health priority (associated with DRC, rather than Uganda).

Covid-19

Reflecting the contemporary context and contours of the global pandemic, many respondents referred to Covid-19 as the 'killer disease' or 'current disease'. They noted that they learnt about it from the media, or social media. Attitudes towards Covid-19 shifted markedly from early perceptions.

During the first nationwide lockdown, respondents reported widespread Covid-19 denialism, since there were no (officially reported) deaths in the West Nile sub-region. Whilst Covid-19 was initially thought to come from China, it was later associated with truck drivers. Fears were raised when public press releases divulged positive tests from truckers passing from Kenya and Tanzania.

Accordingly, there was resistance to many of the restrictions which came with the lockdown, and adherence to SOPs (mask wearing, hand washing, use of masks), was low. Reportedly, among those that did adopt these measures, adherence was largely because of police enforcement, e.g. forcing people to wear masks at checkpoints. Some family heads also undertook their own initiatives aimed at disease prevention, for example putting hand washing stations in homesteads and buying soap, which reportedly led to family-wide observance of specific SOPs.

Many respondents also noted resistance and rejection of restrictions to burial modifications. This was sometimes based on "scientific" arguments, for example, one female respondent questioned whether a dead body could spread the virus, " scientifically the veins of a dead body have collapsed as such after disinfecting the body it remains un-harmful therefore attention should shift on social distance but not keeping the dead away from people." Others questioned the socio-moral implications of burial restrictions. One female respondent, who's

relative in Kampala died from Covid, explained: "*the body was transported to their village in Maracha. The manner in which the body was protected and buried in un usual way - by a team of people that escorted the body, dressed in overalls and buried hurriedly. We had organized prayers awaiting the body at Christ the King chapel in town but got disappointed when the body was purposely delayed until night…. Back in the village no access was granted even to the closest relatives."*

Covid-19 made a significant impact, cited my numerous interviewees as being more significant than HIV/AIDS and Ebola. Covid-19 presented significant difficulties in terms of the delivery of care, since most Aruans live more than 5km away from medical facilities. Facilities too were under-staffed - despite exemptions, many health workers reported fearing to travel to work during periods of lockdown, because of reported 'torture' conducted by security forces.

This was often attributed not to the scale of mortality, but to the restrictions which affected wider economic and social aspects of life. Food insecurity was offered as a particular barrier to lockdown adherence. One herbalist explained "*COVID 19 has brought fear in people and the restriction has increased poverty levels since traders find it difficult and more expensive to travel for business, other closed their businesses, school age children getting spoilt at home by marrying off, conceiving from home among others."* Respondents explained that rarely do households subsist on their own land as in the past. Another female respondent explained the issues with a forced return to farming: "*This lock-down has left us especially me with mostly garden work to do for survival. I no longer move for fish business because of the fear of covid-19 since in the open vehicles it is not easy to maintain social distance. So to avoid get covid-19 I have resorted to farming and our president supports farming more than all activities but the difficulties faced here is the fact that weather determine the yields of our crops is on great challenge being faced. Adding to this while the crops are yet yielding, life is a struggle unlike if business was not risky, money is easily got to sustain living compared to farming that is restricted by weather and crop season."*

The contradictions in policies were also noted. Several respondents commented on the hypocrisy that local movement was restricted when long-distance trucking (across international borders), continued. Another female respondent lamented the "moral decadence" of policies whereby churches were shut whilst markets remained open. In sum, whilst clear directives from Presidential leadership were lauded as beneficial during HIV/AIDS, and often presented as an example of good epidemic preparedness, clear

leadership during Covid-19 was explained as detrimental to survival, since it compromised well-being.

During the later stages of research, Covid-19 vaccine administration had begun in the district. Our interviewees reported widespread hesitation, fears, or resistance to getting a vaccine themselves, or within their communities. In particular there were fears about the side effects of the vaccine, fears related to mortality from the AstraZeneca brand vaccine, as well as vulnerabilities created by pre-existing conditions. One male Arua resident summarised: *"vaccines reacts badly or even kills a person who has some serious sicknesses like blood pressure, sugar diabetes, ashma and HIV AIDS once vaccinated."* There was significant enthusiasm for other cures, particularly herbal ones. A herbalist explained that he treats the virus through stewing a syrup out of combination of ginger, garlic, young eucalyptus leaves, mango leaves, lemon grass, asthma leaf plant. Another women explained that COVID could be treated with a chloroquine injection or tablets.

Other Disease Outbreaks

In addition to externally defined disease outbreaks, many respondents noted that other epidemics affected area. These included hepatitis-B, cholera, meningitis, smallpox, plague. Life histories revealed deep memories of epidemics, which were reportedly managed through locally-devised solutions, often with recourse to herbal medicine. Several respondents noted that small-pox and tetanus, which is now controlled by vaccination, was previously managed herbally. Several noted that the resilience of herbal treatment meant that, even today, herbalists were consulted alongside biomedical facilities.

Previous epidemics, were often referred to using Lugbara terms, which corresponded to particular sets of recognisable symptoms:

- Measles (kejuka) –" signs like skin rushes all over the body and mostly in children, diarrhoea, vomiting, red lips making it difficult to eating because of mouth sours and more severe in children who were not vaccinated"

- Smallpox (ingulua) – "sign was blisters on the body and attacks all age groups unlike measles. The blisters appeared like a burn with fire and when it bursts one would feel serious pain."

- Trauchoma (nyami). "This presented with reddish eye, and said to have originated from Sudan brought by traders who moved between Uganda and Sudan"

- Gonorrhoea (njuku). “This was said to have originated from Congo and is sexually transmitted – it is associated with business in town and Congolese women who were said to have brought this.”

Memories of managing cholera, which has long and intermittently affected Arua’s overcrowded urban areas, was mentioned with reference to effective local strategies to containing disease outbreaks. Whilst memories of isolating for new diseases remained, notions of specific herbal medicines were not held by the general population.

Multiple elderly respondents often invoked earlier responses to epidemic containment as contrasts to COVID-19 blanket lockdowns. A retired teacher explained: “*As soon as a disease outbreak is noticed, communities start devising means to control its spread and they do so by isolating victims and keeping them in quarantine for example around 1950s diseases like small pox and chicken pox were common. Lugbara people used to isolate homes with victims of small pox by tying ropes around homes or a house where the victim lived an indication of, “no go area” to allow the victim undergo treatment without any interaction with outsiders or other family members which was strictly followed until one cured. The victim will only be provided food and medicine by the family or a member of the family for the required period or until the victim cures from the disease… this was strictly observed and accepted practice to control spread of any air born disease unlike today where cases of people suspected with COVID 19 run away from quarantine centres or hide their status in fear of forced quarantine, stigma or the need to look for survival*.” The resurgence of “indigenous lockdowns” in Arua must be understood as a locally-constituted response, and subversive form of resistance, to government imposed Covid-19 lockdowns.

Key findings: Moyo

In total, 37 interviews were conducted within Moyo, including with 16 biomedical personnel (doctors, nurses, clinical officers, technicians and other allied healthcare professionals), three herbalists/traditional practitioners, seven local leaders, and eleven community members (including fishing-farmers, pastors, teachers, students amongst others[1]).

Health priorities

- When respondents were asked of current health priorities, their responses included numerous endemic diseases (rather than epidemic diseases). Malaria was reported as the most common health concern, along with other infectious diseases (intestinal

[1] Full details on numbers/occupations not given to preserve anonymity.

worms, pneumonia) and non-communicable/ chronic conditions (diabetes/ *Sukari laza*, hypertension, asthma/ *Okolo lokome* and cancer). Other infectious diseases that were noted by some interviewees included cholera, polio, meningitis and lymphatic filariasis.

- For various health concerns, people reported to seek various forms of care, including herbal and biomedical therapies, and religious and spiritual healing. Pathways for seeking therapies varied, but for instance, while biomedical practitioners would manage conditions such as diabetes, hypertension, herbalists are sought to treat conditions such as headache, diarrhoea, wounds; religious healers managed epilepsy and possession; and *ojo's* managed forms of witchcraft and poisoning. Of note, when describing accessing care, Village Health Teams and Herbalists were particularly important actors in providing healthcare.
- Medical personnel noted that vaccinations had largely controlled and allayed fears from other diseases (including hepatitis B, and prior to that, Yellow Fever).
- When outbreaks of infectious disease were noted – for instance cholera, Ebola, amongst others – these were said to have originated elsewhere. It was widely recognized that the borderland location meant they were 'prone to epidemics'. Cross border movements, including for trade, through formal and informal routes was seen as a 'conduit for disease transmission'.

Histories of epidemics and response

HIV

- HIV was initially known as *Okolo hwaa ri i'* before being known as *urwea/ obu urwea* (Ma'di term) or *Slimu,* due to the wasting characteristically seen in early years of the epidemic.
- While HIV emerged in the 1980s, it became visible in the 1990s in the region. Narrative histories of HIV were notably entangled with periods of movement and conflict. For example, one medical professional reported that HIV emerged in the region during a time of social upheaval in the 1980s, and interestingly was subsequently associated both with the conditions of protracted conflict and, into the 1990s, as a 'disease of the elites because they were the people who had assess to movement and luxury'.

- In particular, HIV was referenced during periods of returning from exile (normally southern Sudan as it was then, or DRC), and long-distance travel. It's transmission was largely acknowledged to be through (hetero)sexual contacts.
- As one doctor noted, HIV 'became a human rights issue', due to its visibly high mortality.
- Before the introduction of antibiotics for opportunistic infections and anti-retrovirals, HIV was associated with witchcraft with local therapies sought ('traditional' treatments including from herbalists). One cultural leader noted that herbalists would treat various opportunistic infections now associated with HIV. With the advent of treatment protocols for opportunistic infections and ARVs, treatment pathways shifted to biomedical sources.
- The government's response to HIV/AIDS in the 1990s was noted; from abstinence campaigns to ARVs. The introduction of diagnostics *and* interventions (particularly treatment) shaped social responses to HIV, allaying prior fears and uncertainties.
- How people sourced knowledge about HIV had evolved since the emergence of the viral disease. In the 1980s, people referred to testimonies of *Philip Lutaaya,* a Ugandan musician who publicly declared his HIV-positive status. For younger generations, people heard about the disease mainly from school, and other public information sources.

Ebola

- While Ebola was the common name used by most respondents, some referred to it being given the terms *oya-iza laza/ Laza esule oyaru rii',* meaning the disease from monkey meat/ from monkeys, *Laza arikuyi ruasi rii''*, meaning blood haemorrhage or *Dratuyi,* meaning a fast-killing disease.
- Ebola arrived in the 2000s in northern Uganda.
- Outbreaks have been in neighboring areas and not directly impacted people living in Moyo district, and respondents noted this. However, given the visibility of the disease associated with bleeding and death, it did evoke a sense of panic for some.
- It is notable that some medical personnel participated in the response to Ebola outbreaks, including in Gulu in previous years, and were called on as experts to advise countries MoH in the response to Ebola in West Africa (2014). Ebola is known to be transmitted primarily by contact with bodily fluids, particularly blood, or through eating

primates. It was acknowledged that healthcare workers were at risk for contracting Ebola.

- People sourced information on Ebola largely through mass media outlets, or through direct experience of working in the healthcare system.

COVID-19

- COVID-19 was referred to normally as *corona/Korona,* or *Laza China dri rii/ China ni laza (*sickness from China) *or Laza mudrilimbi dricalu* ('19 disease). While Ebola outbreaks have been linked to geographical regions, COVID-19 was identified as a 'worldwide phenomenon'.
- The global spread of COVID-19 infections led to fear about people returning to the region from other countries, particularly from Asian countries, or Europe (including Italy).
- Transmission was noted as being airborne, and thus 'public compliance' with SOPS/ Standard Operating Procedures (mask wearing, handwashing) was recognised as important by healthcare workers, with one consequence of the pandemic being an increased attention to household hygiene practices.
- Information and messages about COVID were largely spread through mass media outlets (TV, radio) and social media platforms (facebook, WhatsApp).
- COVID-19 was seen by all respondents as severe given local and global social, economic and political impacts. The perception of severity was a reflection on the restrictions on movement that were put in place to contain the spread and impact of COVID, as well as the impact on households and individuals beyond morbidity and mortality (that is, the economic impact on households and individuals, closure of schools, loss of income, reports of domestic violence and suicide), and its global impact. While individuals and communities may not have been directly affected by coronavirus disease, they were affected by the social restrictions and the economic and social impacts of this were a major concern.

Some of the themes identified in the interviews showed layered narratives across the three viral diseases:

- Numerous *Ma'di* names were used for various epidemic diseases, some of which have been detailed above.
- Stories were narrated of individuals first known to have contracted the high-profile infectious diseases, akin to the identification of a 'patient zero' (for HIV, a businessmen travelling to southern Uganda; for Ebola, returning soldiers from DRC; and for COVID, people travelling to the region from other countries including South Sudan, and Dubai)
- Thus, these diseases tended to be imported across borders/ elsewhere, and associated with movement and/or particular occupations (businessmen, truck drivers).
- The visible symptoms were notable in the emergence of HIV and Ebola in particular (wasting/ slimness in the case of HIV, bleeding in the case of Ebola). While COVID was associated with high fever and flu-like symptoms, the effects of COVID were seen through the impacts of lockdowns.
- While family members, and people within the community, were important sources of information on HIV during the early years of the epidemic, mass media outlets and social media were increasingly reported as the main sources of information on Ebola and COVID respectively. Knowledge was also formulated at times of burials.

Health systems and Public health in times of COVID

"A lot of attention is given to patients with epidemics, rather than other sicknesses. Response is geared towards management of epidemics" (Healthcare worker, Moyo).

- Within the context of longer-term health system constraints (on resources, costs of treatment, and access to referral – with limited ambulance provision through community mobilization), epidemics changed the provision of routine healthcare – with disease outbreaks leading to shifts to 'emergency' and urgent care.
- During COVID, the provision of health services shifted to COVID-19 care and needs for quarantining patients. Supplies of certain materials improved at points, for instance, a technician noted that "*Before the emergence of corona, many inputs like protective gears have been inadequate, but now enough personal protective equipment (PPEs) are fairly available for instance many development partners have printed lots of masks with their logos for visibility but around two months in May-July, 2021 there were inadequate sanitizers.*" On the other hand, the same technician reported that other aspects of infection prevention control, including waste disposal, were limited.

- The public health response was seen as a government response, with support from WHO and partners.
- Lockdowns had implications for provision of services (including preventing patient's gathering in waiting rooms) and for public health intervention programmes – e.g. Human Papilloma Virus (HPV) programmes, as children were not in school and people couldn't gather in groups for such public health programmes.
- Prior experiences of epidemics were important in informing knowledge on ongoing and emerging epidemics. This was not just through the spatial and material proximity of various viral infectious diseases and public health control techniques. Medical personnel drew on experiences and expertise from Ebola in their response to COVID - team members were retrained and preparedness measures adopted.
- There were political critiques to the lockdown measures, and resistance/ambiguity towards COVID vaccination (with safety concerns on externally manufactured vaccinations). There were incidents of resistance to public health measures to contain COVID-19, including quarantine centres for infected people, and resistance and mistrust towards vaccinations which originate outside of the African continent.
- In these critiques and resistance, there was a notable disjuncture between ideas of 'local' and (global) 'public health'. This was also seen in critiques on unequal power dynamics in *knowledge and expertise.* While on the one hand, Ugandan medical practitioners were called on as experts in the later West African Ebola outbreak, one doctor noted how, despite a desire to conduct epidemiological studies on Ebola in Gulu in the early 2000s, resources were limited for national staff. They reported however, that interventions and studies were conducted by 'expatriates' and international organisations. Rumours spread on the true nature of the interventions by Europeans, as reported elsewhere for other public health interventions, and carry forward in perceptions on the mistrust towards COVID vaccination.

Summary of Project Findings

In seeking to understand health-seeking practices along the borders of Uganda-DRC and Uganda-South Sudan, our findings illustrate how borders structure health seeking in specific ways. Borders have long been inscribed with a boundary over which disease and other health threats spread, as have metropolitan urban centres and memorable populations

movements. Longer fears of managing disease outbreaks from Congo and South Sudan have been reactivated in response to new epidemic threats (see also Leonardi, Storer and Fisher 2021). Along the borders, everyday movement transgress ideas of harm. People's experiences and the everyday is inherently tied to the borders, and the geographical and historical social, economic and political marginalisation forms intersections of structural inequities and social stigmatisation. Pluralistic health-care seeking is the norm, with clan and family decision-making central in structuring care decisions.

In exploring how knowledge is produced in relation to epidemic threats, our findings show how both citizens and health workers effectively differentiated between transmission of HIV/AIDS, Ebola and COVID-19. However, continuities emerged. First, in how the diseases were understood. Signs of these diseases were differentiated by their transmission, or their visible effects on the body. For example: "Ebola blood comes out through all openings of the body, COVID-19 is got when close to one another, HIV is sexually transmitted". Second, all three diseases were understood as external to the region, coming from outsiders, or border-crossers. Third, there was a lag time noted between public health information being administered, and local evidence supporting such explanations.

Taking a historical perspective, HIV/AIDS was understood in relation to the state and its involvement in providing therapies that have dramatically changed the fortune of people affected. This has had significant effect in the understanding of subsequent emerging diseases in West Nile, most notably Hepatitis B (Pearson and Storer, forthcoming). The visible bodily effects and high mortality rates seen with HIV/AIDS, dramatically reduced following the introduction of anti-retrovirals now widely available in the region. Subsequent patchy provision of healthcare resources to respond to other disease outbreaks is therefore evaluated alongside the 'successes' of ARVs and HIV/AIDS. In a forthcoming article, Pearson and Storer put forward the notion of *epidemic palimpsest* as the "collective repertoire of experience and memory, over which new health interventions take hold. a consequence of biomedical 'projects of power' and everyday resistance to histories of marginalisation". Epidemic responses, in their ability to attract funding and the work of state agencies and international donors, hold a privileged place within repertoires of interpretation, which can be activated in subsequent "emergencies". This is illustrated by the words of a woman in Adjumani, speaking with Georgina Pearson during her PhD fieldwork in 2009:

> *"Those with HIV, we would shake [their] hands. The AIDS of those days, people used to fear it—before ARVs, it would be a short time before you died. When the drugs came, people stayed and they treated it like malaria. But hepatitis B spreads quickly. For HIV, even if you stay with someone and don't have sexual contact, you will be okay. 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 they could take the drugs. With hepatitis, there are no drugs, 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."*

While for HIV/AIDS and Ebola, the high mortality was a particular threat contained through public health intervention (promotion of 'ABC' and ARVs for HIV, and quarantine and safe burials for Ebola), for COVID-19 the impact was felt much more widely with the response understood as unprecedented since the response brought widespread disruption to socio-economic well-being.

Overall, our findings bring evidence from epidemic responses including HIV/AIDS, Ebola and COVID-19 to discussion of future pandemic preparedness. First, they map the unfolding production of panic around new viruses with "no cure", reviving memories of HIV/AIDS in the 1980s and early 1990s. Second, they bring to attention the recycling of stigma towards outsiders, for instance truckers, across perceptions of 'risk' and 'risky behaviours' in relation to infectious disease outbreaks (Storer, Dawson and Fergus, 2022). Third, they show how the phasing of awareness, testing, and treatment opportunities can create, rather than abate, uncertainties, with implications for social responses to healthcare interventions (Pearson and Storer, forthcoming). Fourth, they situate socio-economic determinants of health and national inequalities in epidemic containment in relation to epidemic containment strategies. In doing so, they caution how health responses may lead to fostering mistrust – with a need to reflect on the potential legacies of COVID-19.

Concluding Remarks

'Living the Everyday: Health Seeking at Uganda's Margins' sought to explore perceptions and reactions of the Ebola response in a neglected part of Uganda. The impetus for the grant at the time of writing the proposal was the then ongoing Ebola outbreak in Eastern Democratic Republic of Congo (DRC), which threatened to spread into Uganda.

Understanding the reception of this response in Arua/Moyo, border districts and towns in the North West sub-region, West Nile, would have been key to mitigating the spread of Ebola in Uganda. In West Nile, public health generally arrives in 'emergency mode', and we intended to understand how such provisioning interfaced with actual approaches to

managing ill-health, as well as multi-layered epidemic/infectious disease responses (HIV/AIDS, Hepatitis B and Ebola). The subsequent onset of COVID-19 in 2020, both shaped the direction of the grant and made our originally planned ethnographic fieldwork impossible. We therefore proceeded with a remote model of fieldwork, where Ugandan research assistants in Arua and Moyo drove the research, based on co-designed, in-depth survey instruments which documented responses to COVID-19 in addition to previous epidemics.

Drawing on this new research and building on longer-term research carried out in the region by the lead research team, our findings contribute to scholarship relating to quests for therapy in West Nile, and epidemic responses more broadly. The Ugandan research team examined the concept of indigenous lockdowns, providing an historical exploration of epidemic containment in Arua. This is significant context for understanding social resistance to public health measures (including social distancing, lockdown and vaccination drives) during COVID-19. An accurate predicator of whether public health measures will be resisted is the extent to which measures themselves conflict with individual and communal well-being. For West Nilers, ‘health’ is a broad notion which encompasses multiple dimensions of physical, psychological, social and economic survival. All of these dimensions must be taken into account when developing epidemic interventions, and assessing their feasibility in the sub-region.

In our work, we thus extend a historical focus on epidemic threats. Analysing the ‘emergence’, and trajectories of understanding ‘new’ viral threats and public health campaigns to contain and control, we examine how memories and experiences of managing prior afflictions (HIV/AIDS prior to the widespread availability of anti-retroviral therapy), and propose a consideration for ‘epidemic palimpsest’ as a repository of experience through which new viral conditions are made legible, particularly when the rollout and underfunding of public health campaigns brings uncertainty (Pearson and Storer, forthcoming). Public health interventions regarding epidemics are often incomplete, and can create panic and uncertainty. It is particularly problematic when attention is brought to a new disease through testing, but vaccinations/ prevention is not adequately provided or explained. Overall, our research provides empirical evidence which shapes academic understandings of, and policy approaches to, public health in normalcy and emergency in West Nile.

Epilogue

Our research conducted through 'Living the Everyday' raises the profile of the lived experience of populations affected by ill-health and epidemics in a neglected and historically marginalised region of Uganda. For people in West Nile including participants in our research, issues of health and healthcare are entangled with issues of poverty and development and historical marginalisation. While our research is specific to localities in the West Nile region of Uganda, our approach and examination of social responses to, and knowledge formation on, epidemics and threats across borders, will bear relevance for public health policy addressing these concerns in other settings.

Throughout our research, we have supported collaborative working and the training of Uganda research assistants based in West Nile. We worked closely with colleagues in the Uganda UK Health Alliance, particularly Dr Solomon Kamurari. Through the UUKHA, we have established working relationships with colleagues based in West Nile institutions (including Muni University and the Ministry of Health) whom we will continue to develop equitable partnerships with in future research.

Project Outputs

Articles

Elizabeth Storer, Innocent Anguyo and Anthony Odda, (2022) "One man's meat is another man's poison": Marungi and Realities of Resilience in North West Uganda, *Civil Wars*, https://www.tandfonline.com/doi/full/10.1080/13698249.2022.2031440

Cherry Leonardi, Elizabeth Storer and Jonathan Fisher (2021) Geographies of Unease: Witchcraft, Mobility and Insecurity in an African Borderland*, Political Geography,* Volume 90, https://doi.org/10.1016/j.polgeo.2021.102442

Kirk, T., Green, D., Allen, T., Carayannis, T., Bazonzi, J., Ndala, J., Stys, P., Muzuri, P., Nyenyezi, A., Vlassenroot, K., Nyuon, A.D.A., Macdonald, A., Owor, A., Storer, L., Okello, J., Hopwood, J., Porter, H., Oryem, R., Parker, M. and Akello, G. (2021), Crisis responses, opportunity and public authority during Covid-19's first wave in Uganda, the Democratic Republic of Congo and South Sudan. Disasters, https://doi.org/10.1111/disa.12513

Elizabeth Storer and Georgina Pearson (2019) Cross-Border Dynamics and Healthcare in West Nile, Uganda, UNICEF, IDS & Anthrologica [online at: https://opendocs.ids.ac.uk/opendocs/handle/123456789/14582]

Working Papers

Storer, Elizabeth and Pearson, Georgina (2022) *Living the Everyday: Health-seeking at Uganda's Borderlands*. Summary of Project Findings. Firoz Lalji Institute for Africa, London School of Economics and Political Science, London, UK.

Aluma, Clement, Anguyo, Innocent, Storer, Elizabeth and Pearson, Georgina (2022) *Indigenous lockdowns: a historical exploration of epidemic containment in Arua District, West Nile sub-region, Uganda.* Living the Everyday (2022/1). Firoz Lalji Institute for Africa, London School of Economics and Political Science, London, UK. https://eprints.lse.ac.uk/114622/

Aluma, Clement, Anguyo, Innocent, Storer, Elizabeth and Pearson, Georgina (2022) *An enquiry into the use of Covid-19 herbal medicines in Uganda.* Living the Everyday (2022/2). Firoz Lalji Institute for Africa, London School of Economics and Political Science, London, UK. https://eprints.lse.ac.uk/114625/

Candia, Emmanuel and Kamurari, Solomon (2022) A retrospective assessment of Covid-19 viewed from Arua Regional Referral Hospital, West Nile Sub-Region, Uganda: Emmanuel Candia in conversation with Solomon Kamurari. Living the Everyday (2022/3). Firoz Lalji Institute for Africa, London School of Economics and Political Science, London, UK. http://eprints.lse.ac.uk/id/eprint/114627 (Foreword and editing)

Storer with CPAID Researchers, (2020) *Observing Covid-19 in Africa through a public authorities lens.* Centre for Public Authority and International Development Working Papers. Firoz Lalji Centre for Africa, London School of Economics and Political Science, London, UK.

Blogs

Storer and Anguyo, For LSE Africa Blog, (22nd February 2022) Social media and trust in strangers have grown Uganda's market for COVID-19 treatments https://blogs.lse.ac.uk/africaatlse/2022/02/22/social-media-and-trust-in-strangers-have-grown-ugandas-market-for-covid-19-treatments/

Storer and Osuta, For LSE Covid Blog (August 2021) 'Only For African Export': Understanding Vaccine Hesitancy in Uganda, https://bit.ly/3BXauXk

Storer and Fergus, For LSE Covid Blog (June 2021) Understanding how people think about COVID in Africa, https://bit.ly/3A1mC9c

Storer, Pearson and Torre, For LSE Africa Blog (March 2021): Better Health Interventions in Africa means understanding individual and communal practices of care: https://blogs.lse.ac.uk/africaatlse/2021/04/13/