# Linking Climate, Gender and HIV Justice

## A Preliminary Report on Access To HIV Treatment and Care for People Living on Lake Chilwa Islands, Malawi

May 2019

COWLHA

SOUTHERN AFRICA LITIGATION CENTRE

THE GENDER AND JUSTICE UNIT

AFRICA REGIONAL GRANT ON HIV
REMOVING LEGAL BARRIERS

# LINKING CLIMATE, GENDER AND HIV JUSTICE: A PRELIMINARY REPORT ON ACCESS TO HIV TREATMENT AND CARE FOR PEOPLE LIVING ON LAKE CHILWA ISLANDS, MALAWI



**ABOUT THE COALITION OF WOMEN LIVING WITH HIV/AIDS IN MALAWI**

The Coalition of Women Living with HIV and AIDS in Malawi (COWLHA) was established in 2006. It unites different groups of women as a civil society force in dealing with issues on gender and women's rights in the context of HIV and AIDS that impact on the lives of women living with HIV and AIDS in Malawi. COWLHA's mandate specifically seeks to enhance the protection and promotion of rights of women living with HIV and AIDS. At the moment, the membership of the coalition stands at approximately 15000 women living with HIV.
https://cowlhamalawi.wordpress.com/

**ABOUT THE SOUTHERN AFRICA LITIGATION CENTRE**

The Southern Africa Litigation Centre (SALC) is a regional human rights organisation, established in 2005. SALC aims to provide support to human rights and public-interest litigation initiatives in Southern Africa. SALC works in Angola, Botswana, Democratic Republic of Congo, Lesotho, Malawi, Mozambique, Namibia, Swaziland, South Africa, Zambia and Zimbabwe.
http://www.southernafricalitigationcentre.org/

**ABOUT THE GENDER AND JUSTICE UNIT**

The Gender and Justice Unit (GJU) hones in on legal empowerment as one of the most powerful catalysts of gender equality and social justice, both of which are crosscutting and critical to meaningful citizen participation in public life. GJU was established to use the law as a tool for gender equality and social justice. The Unit focuses on working with other organizations and individuals to advocate for systemic change in public law matters, including issues that affect the disadvantaged and advocating for law reform through: research and advocacy, provision of clinical legal services; legislative proposals; innovating around access to justice; and impact litigation.
http://www.genderandjustice.org/

**AUTHORSHIP AND ACKNOWLEDGMENT**

This report was researched and written by Ms Edna Tembo (COWLHA Executive Director), Ms Sarai Chisala-Tempelhoff (Legal Expert, Gender and Justice Unit), Mr Peter Gwazayani (Media Consultant) and Annabel Raw (Health Rights Lawyer, SALC). With thanks to Molly Brossman (SALC intern) and Harry Madukani for input and editing. We are grateful to interviewees who provided information for the report.

This report was made possible through the generous support of the **AFRICA REGIONAL GRANT ON HIV - REMOVING LEGAL BARRIERS**. To implement the Grant, a partnership of organisations has been formed to strengthen the legal and policy environment to reduce the impact of HIV and TB on key populations in ten countries in Africa. These countries are Botswana, Cote D'Ivoire, Kenya, Malawi, Nigeria, Senegal, Seychelles, Tanzania, Uganda and Zambia. Over the past 3 years, the project has worked to assess, strengthen and monitor legal and policy environments for HIV and has provided capacity strengthening opportunities for key stakeholders and decision makers from these countries. The UNDP is the principal recipient of the Grant, which in turn collaborates with SALC, the AIDS and Rights Alliance for Southern Africa (ARASA), ENDA Santé, and Kenya Legal and Ethical Issues Networks on HIV and AIDS (KELIN).

**COVER IMAGE:** Courtesy of UNDP Malawi / Amos Gumulira.

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# Acronyms and Abbreviations

| | |
|---|---|
| **ARV** | Antiretroviral |
| **ART** | Antiretroviral treatment |
| **CAG** | Community ART Refilling Groups |
| **COWLHA** | The Coalition of Women Living with HIV and AIDS in Malawi |
| **DHO** | District health officer |
| **HIV** | Human immunodeficiency virus |
| **HSA** | Health surveillance assistants |
| **NGO** | Non-governmental organisation |
| **SALC** | The Southern Africa Litigation Centre |
| **TB** | Tuberculosis |
| **UNICEF** | The United Nations Children's Fund |

# Executive Summary

This is a preliminary report on barriers to access to HIV treatment and care experienced by communities living in and around the Lake Chilwa area in Malawi.

A fact-finding mission was undertaken in August 2018, which confirmed that seasonal drought and environmental degradation in the area exacerbate existing barriers to access to HIV treatment and care. While initiatives have been undertaken to address some of these barriers, there remain barriers that are likely to persist and re-arise on a seasonal and ongoing basis.

This report makes a number of recommendations based on these preliminary findings.

# Introduction

There have been frequent reports in recent years on the plight of communities living in and around the Lake Chilwa area in the Southern Region of Malawi. In August 2018, the Daily Times newspaper ran a front page article entitled “Left to Die” that described communities in Lungadzi, Ngotongota and Chingoma in the traditional Authority of Mwambo that were cut off from the Zomba District mainland in areas between the lake to the west and the Mozambique border to the east.[1]

The news article described a number of deprivations suffered by the communities but, in particular, highlighted that people living with HIV were unable to access antiretroviral treatment (ART) and experiencing frequent breaks in treatment in the result. The article featured accounts of people living in the area going without ART for two weeks to two months at a time because of the absence of services that were accessible to them in their communities. The community members described that they were reliant on travelling long distances at significant expense to access treatment in either Phalombe in Malawi (requiring travel through Mozambique to get there) or from clinics in Mozambique where they weren’t guaranteed a right to access care as Malawi citizens.

Travelling through the Lake by boat or canoe had become impossible due to the Lake drying, leaving kilometres of mud. The cost of taking a motorcycle from Kungadzi to the Nambazo Health Centre, for example, was costed at about MWK6,000 by motorcycle, an inhibiting cost for impoverished community members. The article quoted the Zomba District Health Officer (DHO) as saying there was little the government could do to better service the communities due to the condition of the Lake.

[1] C Jameson “Left to Die” *The Daily Times* (3 August 2018).

The Coalition of Women Living with HIV in Malawi (COWLHA) was concerned with these reports and sought to investigate the nature and extent of the problem reported to determine how best the community members' needs could be addressed. This report documents the findings of COWLHA, who travelled to the affected areas to investigate, with support from the Southern Africa Litigation Centre (SALC) through the Africa Regional Grant on HIV: Removing Legal Barriers and the Gender and Justice Unit.

This report is concerned with access to HIV treatment and care. For the purpose of this report, we use the word "access" to mean the ability of individuals to obtain and utilise services and treatments to improve their health.[2] We understand that access is sustained when affordable, high quality, integrated, equitable, comprehensive treatment services are universally available in an environment that is safe, well-informed, confidential, and respectful of the individual and takes specific consideration of the needs of women and girls.[3]

MALAWI'S PREMIER DAILY

The Daily Times

Established in 1895 — For News You Can Trust — Friday, August 3, 2018 — K600

'He is failing to ensure accountability and transparency'

MZ councillors seal mayor's office—P3

'The fuel price hike was chewing into our daily revenue'

Pump price hike impact—P9

'Our children often fall sick'

Long wait for muddy water—P8

TIMES FRIDAY SHAKER

LEFT TO DIE

Separated from Zomba District mainland by Lake Chilwa, the people of Lungadzi, Ngotangota and Chingama, in Traditional Authority Mwambo, are condemned to avoidable deaths as access to health care, education and agricultural extension services remains a far-fetched dream. JAMESON CHAULUKA shares insights into how the people have been cut off from civilisation with no supply of life-prolonging drugs such as ARVs, schools, potable water and agricultural extension services among others. He writes:

ROBERT Mwalama — who is also Village Head Chisoni, Traditional Authority Mwambo, in Zomba District — tested HIV positive in 2017 and was, right away, put on antiretroviral (ARV) drugs.

However, it sometimes takes between two weeks and two months before Mwalama takes his treatment, a development blamed on the long distance he has to cover from Lungadzi location to the point of supply of the drugs — in this case, either health centres in the neighbouring Mozambique or at Nambazo Health Centre in Phalombe District.

"It is not a secret that I am one of the people who get ARVs in Mozambique or, sometimes, at Nambazo Health Centre in Phalombe District, Malawi. Access to ARVs is a big challenge here. We have to get into Mozambique territory twice to get the drugs from Phalombe and it's a very expensive adventure. As I am speaking, it has been weeks since I took the pills," Mwalama said.

Sadly though, Mwalama's story is echoed by scores of people in Lungadzi, Ngotangota and Chingama areas, all of which are part of Zomba District.

These areas are separated from mainland Zomba District at Kachula by Lake Chilwa while the other side of the areas boarders Mozambique.

The only direct route from mainland Zomba to these areas demands that one should cover a distance of 60 kilometres across the lake, which is done either by boat or canoe.

The route ordinarily takes two to three hours on the waters but, as the lake is drying up and no boats and canoes are operating between Kachula on the Zomba mainland and these areas, health and education services delivery is at an all-time low.

It is as if the people have been forgotten in their own country.

Movement from one place to another, which was already a nightmare for people in these areas, is getting more problematic than ever. As things stand, the only practical

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MWALAMA—It is weeks since I took my last pills—Picture by Jameson Chauluka

From front page

route to Zomba and neighbouring Phalombe District for residents of Lungadzi and Ngotangota is covering the distance by land, which means cutting through Mozambique.

Needless to say the Mozambique route is tiresome and intimidating for the locals.

Zomba District Health Office also meets challenges when it comes to transporting hospital supplies including the ARVs to health units under its watch in these areas.

Lungadzi has one under-five clinic, forcing adults, most of them live below the poverty threshold of one United States dollar a day [about K734], to cough over K6,000 in transportation costs.

Motorcycles have emerged as the convenient means of transport from Lungadzi to Nambazo Health Centre in Phalombe. Which means, every time a resident falls sick, K6,000 goes down the drain for, otherwise, free services in public hospitals.

Cederick Kokani, Chisi Ward Councillor — who is also Chairperson for the Health and Environment Committee of Zomba District Council — acknowledged that there are high default rates of ARVs in Lungadzi, Ngotangota and Chingama.

Kokani says this is because the drugs are not easily accessible to people of these areas.

"Those areas are facing huge of problems, when it comes to access to ARVs and other health services. The ARVs hardly come [from the point of distribution]. The people rely on health centres in Mozambique but, in most cases, they are sent back. They can spend a month, sometimes longer than that, without getting and taking the drugs," he said.

But pharmacist, Isaac Packson, has described the ARV treatment breaks as suicide.

Packson said such breaks change the structure of the HIV virus, such that the drugs do not

TIMES FRIDAY SHAKER

Left to die

UNHYGIENIC—John walks with a bucket of water drawn from Lake Chirwa—Picture by Jameson Chauluka

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"Treatment holidays are fuelling HIV and Aids-related deaths. Treatment holidays such as these give the virus an opportunity to change its structure. What this means is that, when you take the same medicines again, they find a new type of virus, and not the one they were made to deal with," he said.

Zomba District Health Office spokesperson, Arnold Mdaliza, while acknowledging that access to ARVs remains a challenge to people in these areas, said there is nothing his office can do about it because transportation challenges are beyond the office's control.

He said his office can no longer afford to send the drugs using boats and canoes as the lake has largely dried up, adding that the government cannot afford to construct a bridge across the lake.

Mdaliza said it is also not easy for the government to send the drugs though Mozambique, saying it is a sovereign country with its own laws.

"There is no means of transporting the drugs that side. The lake has dried up and a health worker cannot walk in mud for over 60 kilometres to deliver the drugs. We cannot send a health worker to be stationed there. Even you [referring to the reporter] cannot accept to work there. How will he take his personal belongings there? We ask the people there to come upland to receive their drugs if they can, at least until water levels rise again in the lake," he said.

On top of condemning people living with HIV in Lungadzi, Ngotangota and Chingama to death, the drying Lake Chilwa has also brought serious water problems to these communities.

Malawi Health Equity Network Executive Director George Jobe said it is heart-breaking that while some Malawians have easy access to drugs, others are struggling to find drugs.

He called on government to find ways of reaching out to these areas with drugs including ARVs.

Ministry of Health spokesperson Joshua Malango asked for time to check with Zomba District Health Office saying it was his first time to hear about the issue.

Malango, however, did not come back to us as we went to press despite promising to do so.

The water table has sunk so low that those who drill boreholes struggle to reach the water table.

It is women who bear the brunt, as they are forced to cover long distances — on foot, of course — in their endless search for potable water.

Caught between a rock and a hard place, women and children are drawing contaminated water for domestic use from swamps that the lake has become.

Mary John lamented that finding safe water has become a problem.

John said she spends most of her time looking for water, instead of attending to other business.

"As you can see, cattle are feeding, drinking and dropping

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**IMAGE 1: REPORTING ON THE SITUATION IN LAKE CHILWA IN THE DAILY TIMES, 3 AUGUST 2018.**

[2] United Nations *Women Key Barriers to Women's Access to HIV Treatment: A Global Review* (2017), available at: http://www.unwomen.org/-/media/headquarters/attachments/sections/library/publications/2017/key-barriers-to-womens-access-to-hiv-treatment-a-global-review-en.pdf?la=en&vs=3431.

[3] *ibid*.

# Methodology

This report was compiled by COWLHA, SALC and the Gender and Justice Unit using a combination of desktop research and in-person interviews.

In-person interviews were conducted in August 2018 by a team comprising Ms Edna Tembo (COWLHA Executive Director), Ms Sarai Chisala-Tempelhoff (Legal Expert, Gender and Justice Unit) and Mr Peter Gwazayani (Media Consultant) who went on a fact finding mission to Zomba. The fact-finding team adopted a deliberate approach of engaging with the District Health structure, the affected communities and the supporting non-state actors. The team wishes to express its gratitude to all who provided assistance and information. The following individuals and institutions were interviewed:

1. The Director of Health and Social Services for Zomba, Raphael Piringu.
2. The Public Relations Officer for Zomba District Health Office, Arnold Mndalira.
3. ART Coordinator for the Phalombe District, Evance Njaidi.
4. Three community members living with HIV from Ngotangota, Zingo Village and Namalele Village.
5. Non-state service providers, Dignitas.

**IMAGE 2 - THE FACT-FINDING TEAM ON THE EDGE OF LAKE CHILWA**

# The Lake Chilwa Area

Lake Chilwa is in the Southern Region of Malawi in districts of Machinga, Phalombe and Zomba and is home to about 1.5 million people.[4] It is the second largest lake in Malawi and stretches between both Malawi and Mozambique. The Lake is situated between the Malawian shire highlands to the West and the Mozambique border on the east. The size of Lake Chilwa varies seasonally and between years, sometimes drying completely.[5]

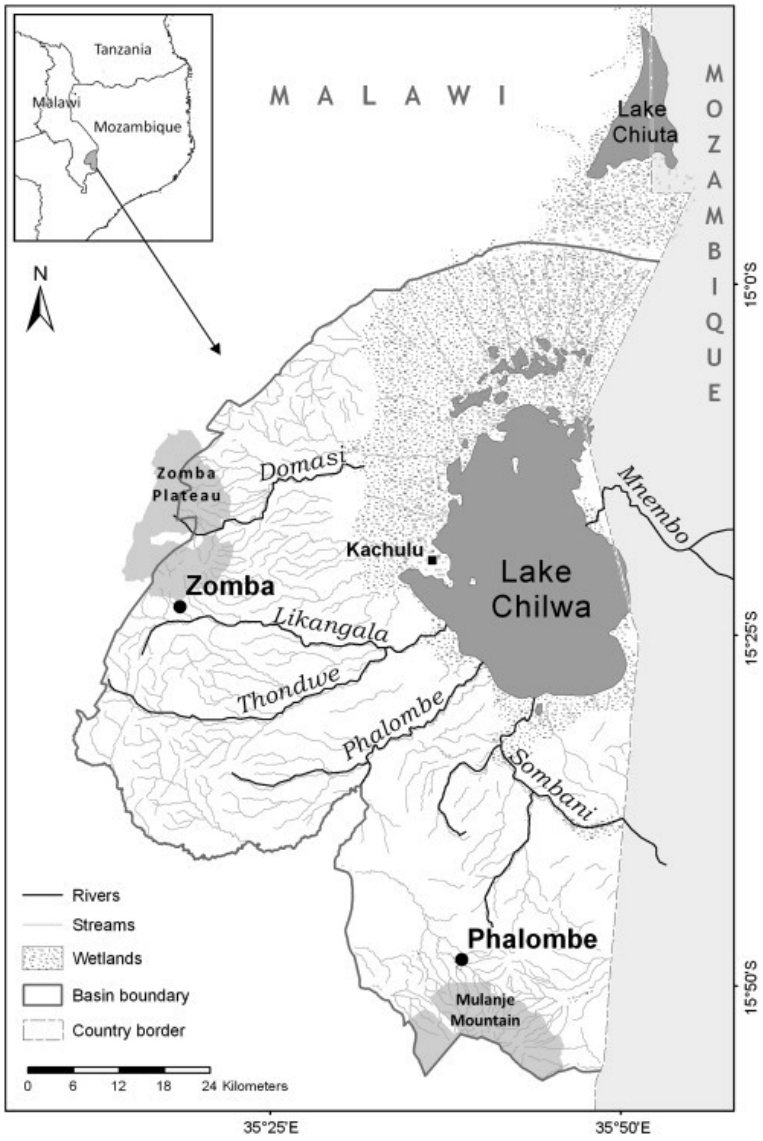


**IMAGE 3: MAP OF THE AREA**

[4] SS Chiotha et al *Lake Chilwa Basin Climate Change Adaptation Programme: Impact 2010 – 2017* (2017).
[5] F Njaya et al "The Natural History and Fisheries Ecology of Lake Chilwa, Southern Malawi" *Journal of Great Lakes Research* (2011) 37(1):15-25.

Commercial and farming activity as well as habitation of people in the area varies with the seasons and water levels.[6] For example, the population of Chisi Island has been said to double when fishing yields increase in more abundant seasons.[7] Poverty is high and most people live a subsistence lifestyle growing maize and / or rice.

Declining water levels in the Lake over recent years have been widely reported in the press for creating pressures on communities' livelihoods and on fishing and farming practices in the area. Aerial satellite imagery below shows declining water levels between October 2017 and July 2018. At the time of the visit to the area, engine boats were not able to sail on the water due to the drying of the Lake. While it was possible to navigate certain portions of the Lake by a lighter canoe, these canoes would still be likely to get stuck in muddier areas.

[6] *ibid*.
[7] J Chavula "Lake Chilwa Dry to Cracking Clay" *The Malawi Nation* (31 August 2018), available at: https://mwnation.com/lake-chilwa-dry-to-cracking-clay/.

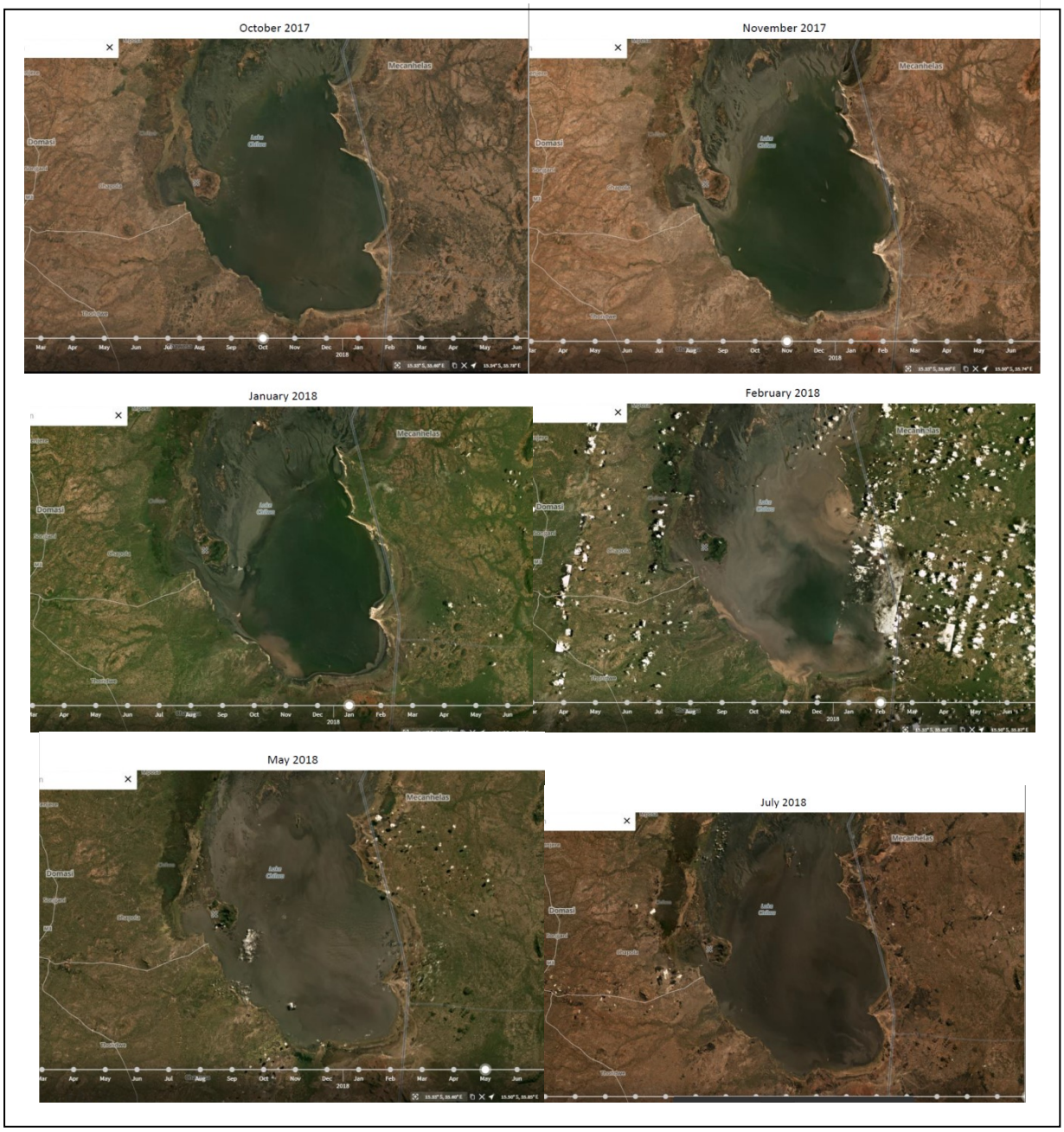


**IMAGE 4: AERIAL SATELLITE IMAGERY OF THE LAKE CHILWA BASIN BETWEEN OCTOBER 2017 AND JULY 2018.**

# Environmental Degradation and Access to Healthcare Services

The relationship between HIV and ecosystem degradation has been described as syndemic.[8] Environmental degradation is connected to increased poverty, malnourishment, migration, and livelihood instability, all of which increases peoples' vulnerability and impairs coping skills to change, factors which may increase peoples' vulnerability to HIV.

HIV may similarly impact the ability of people to sustain themselves through adapting to environmental change including through increased susceptibility to illness, decreased productivity, and costs associated with accessing treatment. Internationally, HIV-affected households are frequently found to be more impoverished and food insecure and therefore more dependent on natural resources as a safety net.[9]

The intensity of environmental degradation in the area and changes in the Lake's ecology over recent years has had both direct and indirect effects on individuals and communities' health.

Direct effects include increased susceptibility to water-borne diseases in periods of drought including cholera outbreaks in 2009-2010 and in 2012. People living on the Lake and in the surrounding areas use the Lake's water for drinking, fishing and ablutions and levels of faecal contamination in the water are high[10] and between May 2009 and May 2010, a cholera outbreak affected the area.

The effect of the degradation of the Lake's environment in inhibiting physical access to healthcare services, commodities and points of care is the focus of this report. It is critical, however, that any response to the immediate problem takes into consideration the syndemic relationship between HIV and environmental degradation in the area and the direct and indirect impacts of climate change and pressure in the long-term on the health of communities in the area.

[8] A Talman, S Bolton and JL Walson "Interactions between HIV/AIDS and the Environment: Toward a Syndemic Framework" *American Journal of Public Health* (2013) 103(2):253-261.
[9] *ibid.*
[10] A Khonje et al "Cholera Outbreak in Districts around Lake Chilwa Malawi: Lessons Learned" *Malawi Medical Journal* (2012) 24:2.

## Restricting Transport to and from Communities

The fact-finding team confirmed that communities living on the shores of Lake Chilwa and on islands in the Lake indeed face significant difficulties with transport and access to services (including healthcare services) during periods of drought, particularly from Kachulu beach to Sombi, Ngotangota and Lungazi.

Drought in the area restricts both the access of non-governmental organisations and State actors that provide mobile healthcare services in the region to access some of these communities and the ability of communities themselves to access other areas where services are more regularly supplied. This was the case at the time of the visit.

For example, the fact-finding team understood from its interviews that periodic visits are made to the relevant areas by the DHOs working with various non-state actors, usually once a month. During periods of drought, these visits become quarterly, with three-months supplies of ART delivered to patients.[11] However, it becomes difficult to transport medications there during dry seasons. The expense of periodic visits and the absence of on-site accommodation for these teams inhibits regular visits. When these regular visits are not possible during the dry season, people from Ngotangota and Lungazi have alternative access to ARVs at Nambadzo H/C in Phalombe District only. This is a distance of 87 km and 37 km away respectively each way.

The negative economic impact experienced by communities during periods of drought further negatively impacts their ability to access alternative modes of transport to travel to the Phalombe district. Reduced earnings during these times means that community members living in the areas between the lake to the West and Mozambique border to the East, in particular, become unable to cross through the Lake to access the Malawi mainland. These communities become reliant on travelling through Mozambique by road to access services in Malawi at significant expense.

For example, CB,[12] from Ngotangota, Zingo Village in the area of T/A Nkumbira, is a member of an HIV support group. CB described that he started taking ART in 2004 said he used to collect his ARVs at Likangala Health Centre. At a later stage, the DHO took the initiative to provide services in Ngotangota and other Islands on Lake Chilwa where he stays. In the three months preceding the time of the visit, however, due to dryness of the Lake, and that health personnel are not frequently supplying ARVs to his area, CB was now needing to collect his ARVs from Nambazo Health Centre in Phalombe at a cost of Mk6,000 for the return trip. CB reported missing medication on some days when he is unable to afford transportation to travel.

[11] COWLHA notes that since the research for this report, six-month refills have been made available.
[12] Names have been anonymised to protect the confidentiality of the respondents.

*"At first I used to get ARVs from medical personnel that used to come here frequently. But since the Lake became un-sailable and that we are no longer visited frequently by medical personnel from the mainland, the nearest and accessible place that I am able to get ART services from is Nambazo in Phalombe. I go using a hired bicycle. It costs Mk6000 to and from," said CB.*

This experience was shared by two other community members interviewed, AA and ZE[13] from Namalele Village from T/A Nkumbira.

*"The challenge is transport to go to Nambazo to collect ARVs because it costs Mk6000 to and from. Health personnel do not frequently visit us as they used to in the past few months due to transport problems. The Lake has become very difficult to cross by boat," said AA.*

The Zomba DHO representatives interviewed did not deny these circumstances or that community members faced barriers to physically accessing treatment. They confirmed that the Lake frequently dries and during those periods, it becomes challenging for health personnel from the mainland to frequently reach out to the people of Chisi, Lungadzi, Ngotangota, Sombi and Chinguma. It was acknowledged by The Zomba DHO representatives that if the Lake dries completely, the community members would have no options but to travel through Mozambique.

The Zomba DHO representatives denied, however, that the community members lacked "access" to treatment on the basis that the Zomba district has sufficient medication in stock. It was described that there is sufficient stock in the district for nine months and together with non-state actors like Dream, Dignitas International, One Community, PACT Malawi, YONECO and PSI Malawi, access to these medications is facilitated, particularly through structures in Ngotangota. The Zomba DHO representatives further sought to point out that their office was undertaking a number of interventions to assist the communities, some of which are described below.

*"My biggest worry at the moment is, in case we do not have enough rains this year to help raise the water levels in Lake Chilwa, what do we do? Maybe we send in advance a lot of ARVs to cover a long period. But the problem comes because those to administer the drugs will be Health Surveillance Assistants (HSAs). How do we monitor the drugs in terms of quality and issues of theft?*
*Now we plan to come to a round table with all NGOs that are involved in issues to do with [sexually transmitted infections] and other health related*

[13] Names have been anonymised to protect the confidentiality of the respondents.

*matters to start strategizing in advance on this matter, the way we have done with issues of cholera preparedness. But as the situation is at the moment, there are structures in Ngotangota to enable people access ART right there.*
*But if the Lake dries up completely, the only way out is that these people from the Islands will have no chance but go to Mozambique side. So the only way is for the two countries to come to a round table and reach a consensus so that going via Mozambique should not be a problem," said Mr Piringu.*

Mr Piringu described that since January to August 2018, the Zomba DHO had collaborated with Dignitas International and other non-state partners to provide ARTs to the area from 8-12 January, 16-20 April, and 23-26 July, with the next visit being due on 17 September 2018.

*"They are going again on the 17 September and they stay there for four days providing ART services," said Mr Piringu.*

Mr Arnold Mndalira, the Public Relations Officer for Zomba District Health Office noted that UNICEF has provided a boat engine to the DHO which is used to facilitate movement in the Lake area. The Zomba DHO representatives also described that they were implementing the following activities with fishermen, sex workers and the general population in the areas since March 2017, together with non-state actors, Dignitas International, PACT Malawi, YONECO, PSI Malawi and One Community: HIV testing services, ART initiation, viral load monitoring, screening and management of sexually transmitted infections, cervical cancer screening, tuberculosis (TB) screening, and condom demonstrations and distribution.

**IMAGE 5: THE FACT-FINDING TEAM'S INTERVIEW WITH THE DIRECTOR OF HEALTH AND SOCIAL SERVICES FOR ZOMBA, RAPHAEL PIRINGU.**

Another initiative the Zomba DHO and its partners described was the use of Community ART Refilling Groups (CAG) that have been set up on islands for when the Lake dries up and health personnel are not able to sail to the islands to administer ART. Zomba DHO respondents stated that the costs for CAGs' transport are shared by the DHO and non-state actors.

*"One member of the group goes to collect ARVs for the rest of the members and they alternate. It is not the same person all the time mandated to collect ARVs for the group. We want them to alternate so that we can be having that chance to check on each one of them, how they are responding to medication. …*

*CAGs are a group of people who have been on ART for some time (say more than six months or a year) and have been found stable (with no complications and responding well to treatment with their viral load decreasing or suppressed). The recommended maximum number of people in CAG is ten, sometimes they can go to 12, but we recommend ten. Because if they are 13, it will be taking more than a year for medical personnel to monitor each and every member of CAG, which is not right health wise. So if you are 12, it means within a year at least once you will have chance to meet with health personnel and have your health status checked," Mr Piringu said.*

The ART Coordinator for Phalombe district, Evance Njaidi, said that they planned to meet with their Zomba counterparts to find ways of establishing outreach clinics right on the Islands during difficult periods.

Since the research for this report in August 2018, COWLHA has noted that the Malawi government has introduced six-month ART refills. This may reduce the number of times an individual has to visit a facility but may nevertheless create a number of other challenges. Challenges may include that people in hard-to-reach areas will not enjoy access to healthcare workers for the purposes of monitoring, viral load testing or other check-ups as frequently.

Civil society organisations have also campaigned for the government to support community adherence support groups that would allow community members to provide peer support and linkage to care in case of problems. These organisations are concerned that the Ministry of Health's nurse-led approach is facing challenges with staffing and logistical problems.

From the above information, it is clear that certain initiatives have been made by both the Zomba and Phalombe DHOs, with support from non-state actors, to service communities in hard-to-reach areas in and around the Lake. These services have also accommodated some necessary flexibility to adapt to seasonal changes in the environment that impacts access to and from the areas inhabited in and around the Lake.

However, it is not clear from the information collected how comprehensive these services are in providing for reliable and consistent access to treatment and care to all isolated communities in the area or only to some areas. The very existence of CAGs, the acknowledgement of officials that patients are left to collect treatment from multiple sites, and the experiences related by the community members interviewed who have to collect treatment outside of the support of CAG structures, indicates, however, that mobile services are not reaching all the affected communities in a reliable, predictable and consistent form. That any number of people living with HIV (at a scale that is not discernible from this initial research) are reliant on travelling across borders at significant personal expense to access treatment is concerning and indicates a lack of adequate access to HIV treatment and care. Pragmatic solutions need to engage the need for both access to ART as well as access to supportive and complimentary health care services.

## Long-Term Environmental Initiatives

The Zomba DHO representatives interviewed emphasised conservation initiatives being undertaken by the Zomba District to prevent the degradation of the Lake and surrounding areas. For example, the forest department and other stakeholders were described as planning to plant trees around the

Lake. It was further stated that the fisheries department had at the time stopped people from fishing in the Lake.

# The Impact on Community Health and Wellbeing

The fact-finding team could confirm that the environmental degradation is negatively affecting the health and wellbeing (including economic wellbeing) of communities in the area, and particularly in relation to its effect on access to HIV-related health services and treatment. However, the precise impact of environmental degradation on community health as a whole could not be measured within the limited scope of the mission.

The Daily Times article reported that deaths had occurred in the communities as a result of persons living with HIV being unable to access treatment. Neither the DHO representatives interviewed nor the community members were able to confirm or deny the reported deaths. The Director of Health and Social Services for Zomba, Raphael Piringu emphasised that his office had no evidence of any deaths:

> *"[I]t was also reported further in the press that some people on ART are dying. But my office doesn't have that data. Those reports were exaggerated because if those reports were true, the person who went to collect that data would have brought evidence, names and all other details of the people that have died due to lack of access to ARVs," said Mr Piringu.*

However due to the current flexible systems through which people living with HIV in these areas access treatment, patient monitoring and data collection may be unreliable.

> *"Normally these people always have two cards for ART, one for Likangala and another one for Nambadzo. They only show up at Nambadzo when they have challenges where they stay. But when the situation normalizes you no longer see them here. For us health personnel it becomes a challenge because we cannot trace them. In our records sometimes we take them as defaulters. That is our biggest challenge. But we always have enough ARVs for everyone," said Evance Njaidi, ART Coordinator for the Phalombe District.*

It is therefore not possible to conclude that the reported deaths did or did not occur. In addition, this indicates that people living with HIV in these areas may not be accessing appropriate monitoring and follow-up to ensure they are able to adhere to and access the supports needed.

# Access Inequality and Gender

It important to consider that the described barriers to access to HIV treatment and care are likely to have a disproportionate effect on vulnerable and structurally marginalised individuals, particularly women and girls.

A recent study by UN Women on women's barriers to access to HIV treatment and care from across the world, shows that women living with HIV welcome the offer of ART but want these interventions to be presented as a voluntary, informed choice in an environment that is confidential, respectful, supportive, and closely connected to community-based resources for treatment literacy and peer support.[14] That study shows that women experience connections between barriers to their basic human needs (inhibited through poverty, insecure housing, lack of decision-making in family contexts and inadequate nutrition) and access to HIV care and treatment.[15]

While not directly discernible from the information collected for this research, it must be anticipated that the extraordinary methods on which people living with HIV in the area are reliant to access treatment during periods of drought and due to environmental degradation, will be inherently exclusionary of vulnerable individuals and may disproportionately impact women and girls. For example, the following factors inherent to peoples' circumstances will pose barriers to using the extraordinary methods of access described:

- Individuals who are not in a position to disclose their HIV status to CAG members due to confidentiality concerns, stigma, personal safety or other factors will not be able to use CAGs to collect treatment.
- Many women and young people will be unlikely to be able to afford the cost and time from family commitments and other productive activities to travel to alternative points of care at their own expense.
- Travelling (whether independently or as part of a CAG) may be reliant on the individual having disclosed their HIV status to family and community-members from whom they may need permission or support to travel.
- Women and girls (whether travelling independently or as part of a CAG) face unique physical and sexual safety concerns to travel alone at long distances to access treatment.

It is concerning that periodic reliance on extraordinary methods of accessing treatment like the use of CAGs, threatens consistent access to health monitoring and care such as viral load testing and addressing treatment side-effects or co-infections. Individuals who are most likely to need supportive healthcare services (such as elderly persons, people who are sick with tuberculosis or not

[14] United Nations Women *Key Barriers to Women's Access to HIV Treatment: A Global Review* (2017), available at: http://www.unwomen.org/-/media/headquarters/attachments/sections/library/publications/2017/key-barriers-to-womens-access-to-hiv-treatment-a-global-review-en.pdf?la=en&vs=3431.
[15] *ibid*.

responding to treatment) are least likely to be able to physically endure the long distances of travel to access alternative points of care.

The nature of the barriers to access to HIV treatment and care to the communities in and around Lake Chilwa are therefore disproportionately threatening to women, girls and other individuals who may experience existing patterns of social disempowerment and marginalisation.

# Discussion

The human right to health requires that health facilities, goods and services must be accessible to everyone without discrimination.

Accessibility has four dimensions: non-discrimination, physical accessibility, economic accessibility or affordability, and information accessibility.[16] Physical accessibility requires that health facilities, goods and services must be within "safe, physical reach for all sections of the population, especially vulnerable or marginalised groups", including in rural areas.[17] Economic accessibility requires that these services must be affordable for all including socially disadvantaged groups.

The provision of essential medications is a minimum core obligation of the right to health as is ensuring the equitable distribution of health facilities, goods and services.[18] The right to health also includes the social determinants of health, such as access to a habitable environment, adequate food and safe drinking water.

From the preliminary information gathered, we are concerned that the right to health, and particularly access to HIV treatment and care, is being violated in the context of both seasonal, periodic drought as well as longer-term environmental degradation of the area. While the State has taken measures with non-state actors' support in an effort to reach some marginalised groups, the information gathered shows that these initiatives may be insufficient. The report indicates that barriers to both physical and economic accessibility persist and that these barriers are likely to disproportionately affect women, girls and marginalised individuals.

We wish to note that in the course of investigating a situation we were alerted to by the article in the Daily Times of 3 August 2018, that the fact-finding team had difficulty confirming a number of

[16] United Nations Committee on Economic Social and Cultural Rights *CESCR General Comment No 14: The Right to the Highest Attainable Standard of Health (Art 12)* (Adopted at the twenty-second session of the Committee on Economic, Social and Cultural Rights on 11 August 2000) E/C.12/2000/4, available at:https://www.refworld.org/pdfid/4538838d0.pdf, para 12.
[17] *ibid.*
[18] *ibid*, para 43.

assertions made in the Daily Times article. Some information was obtained that appeared to directly contradict the Daily Times article and the Zomba DHO representatives stated that retractions of some inaccuracies had been requested. It is not within the scope of the present report to determine the accuracy of the Daily Times article. While we note that the article has positively drawn attention to some critical barriers to access to HIV treatment and care that our preliminary report confirms, we do wish however, to note our concern and call for ethical reporting on issues as sensitive as access to HIV treatment and care.

# Recommendations

This report indicates preliminary findings of barriers of access to HIV treatment and care for people living with HIV in and around the Lake Chilwa area. While there are no indications of ARV stockouts, the investigation did confirm that individuals face barriers to obtain and utilise HIV and health-related services being provided particularly due to environmental degradation and drought in the area that places economic burdens and transport restrictions on certain communities. The investigation shows that existing alternative avenues that have been implemented to enable access when the Lake dries are not sufficient for a number of reasons. This includes barriers based on economic accessibility, threats to confidentiality, the safety of access particularly for women and girls, and inadequate mechanisms for monitoring and complimentary, comprehensive healthcare services.

We make the following recommendations:

**1. Further research:**
There is a critical need for all stakeholders to visit the islands and speak with a larger selection of inhabitants to form a more comprehensive view of the impact of the evaporation, of the environmental degradation, seasonal drought and barriers to access. While, at the time of publication, seasonal rains appear to have temporarily alleviated the situation, it must be anticipated that the degradation of the area is an ongoing concern that will continue to pose long-term and seasonal barriers to access, including economic barriers.

Since the investigation in August 2018, a number of areas in Malawi have faced cyclone-related flooding, which COWLHA has noted to have negatively affected and restricted access to treatment for a number of women in affected communities. While not the subject of this report, COWLHA is concerned to note that climate effects are having a direct impact on treatment access, adherence and health. There is a need for further research on this issue.

**2. Investigation of reported deaths:**
The DHO should urgently investigate the reported deaths in the areas and ensure transparency on its findings.

**3. Equitable and right-affirming approaches:**

There is a need to work with the DHO and the cooperating partners to ensure that their approach to providing services is in line with the human rights obligations and entitlements of the inhabitants and pays particular attention to the barriers to access faced by vulnerable and marginalised groups and woman and girls.

**4. Sustainable access methods:**

The DHO and non-state actors servicing the areas should investigate sustainable access methods that take into account the long-term and seasonable effects of drought and environmental degradation in the area and the syndemic relationship between HIV and environmental degradation. This should include expansion of existing rehabilitation efforts in the areas as well as more focussed interventions such as consideration by the DHO of bidding to develop bilateral agreements with the government of Mozambique to enable eased access to medication and other services for the inhabitants of the affected islands. Consideration should further be made to ensure accuracy and consistency of data for people accessing treatment at multiple points of care.

**5. Press engagement:**

It is important for all stakeholders to engage with media houses and the editors of the Daily Times and other publications to ensure ethical and accurate reporting on such sensitive issues.

**6. Community relations:**

There appears to be a fragile relationships between the affected communities and health service providers. There is need for an interface that brings the community together with the service-providers to air their concerns and develop sustainable, equitable and effective responses to the problems highlighted in this report and concerns raised as a result of the Daily Times article.


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