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Attitudes and Perceptions toward HIV, HIV Risk, and HIV Health Services among Lake Victoria Fishing Communities in Kenya – A Qualitative Study

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CONTENTS

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This report, the *Attitudes and Perceptions toward HIV, HIV Risk, and HIV Health Services among Lake Victoria Fishing Communities-A Qualitative Study*, presents important qualitative findings on the perceptions of the burden of HIV and the access and uptake of HIV health services among these communities. Focus group discussions and key informant interviews were conducted among members of the fishing communities, including fishermen, fish traders, boat owners, and fish processors in nine different beaches along Lake Victoria in Kenya.

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Dr. Martin Sirengo,
Head NASCOP

ACRONYMS

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral Drugs
BMU	Beach Management Unit
CDC	U.S. Centers for Disease Control and Prevention
EGPAF	Elizabeth Glaser Pediatric AIDS Foundation
FESK	Field Epidemiology Society of Kenya
FGD	Focus Group Discussion
HIV	Human Immunodeficiency Virus
IRDO	Impact Research and Development Organization
IMC	International Medical Corps
KAIS	Kenya AIDS Indicator Survey
KASF	Kenya AIDS Strategic Framework
KII	Key Informant Interview
NASCOP	National AIDS and STI Control Programme
STI	Sexually Transmitted Infection
UCSF	University of California, San Francisco
VCT	Voluntary Counselling and Testing
VMMC	Voluntary Medical Male Circumcision

EXECUTIVE SUMMARY

The fishing communities around Lake Victoria in Kenya have been deeply affected by HIV. Previous studies have estimated the prevalence of HIV to be between 21 and 30 per cent among these fishing communities, which may contribute to the high HIV prevalence of the general population in this region. To better understand the perceptions of fishing community members toward the burden and impact of HIV in their communities, as well HIV risk and HIV health services, we conducted a qualitative study in August 2014 among fishing communities in nine beaches along the Kenyan border of Lake Victoria. The objectives of this study were to understand: the roles and responsibilities of members in the fishing communities, their migratory patterns around Lake Victoria, the risk factors for HIV in these communities, perceptions of the burden and impact of HIV/AIDS on these communities, and attitudes toward access and utilization of HIV prevention, care, and treatment health services. A summary of the key findings from the study's focus group discussions and key informant interviews are described below.

Key Findings

Fishing Community Roles, Interactions, and Activities

The fishing communities around Lake Victoria comprise diverse set of roles in order to catch, prepare, and bring the fish to market. Fishermen, who go into the lake to catch fish, are exclusively male, and they are hired to work on a boat by a boat owner. Fish brokers and fish traders obtain their fish from the fishermen and may then arrange for the fish to be processed or manage the sale of the fish. There are fish traders who deal locally by taking fish to the market to be sold, and those who come from far to arrange for the transport of the fish to factories for sale within Kenya or internationally. Fish brokers and fish traders may be male or female, but those who sell to local markets are often female. The processing and preparation of fish is conducted solely by women. Given the high mobility necessitated by fishing, both male and female fishing community members may migrate to other beaches, sometimes even travelling beyond Kenyan borders, in search of fish.

Burden and Impact of HIV on the Fishing Communities

HIV is a common disease in these fishing communities. Study participants stated that a large proportion of their communities are infected with HIV. Participants also expressed that HIV is a more serious health problem compared to other diseases in their communities. This was because many people had died from HIV/AIDS, and though mortality from HIVAIDS has declined with the availability of HIV treatment, some people still perceive having HIV to be a death sentence even with treatment.

The impact of HIV to the infected person and the family unit was described by participants as devastating. Participants stated that HIV made the body weak and

interfered with the ability to work well because of decreased strengthen, the side effects from the medicine, and not being able to work long hours. As such, people with HIV made fewer wages, and this also negatively affected the household income. This lost income, in addition to the financial resources required for medical care, often impoverished families. Furthermore, HIV/AIDS has had a detrimental impact on families, leaving many wives without their husbands and children without their parents.

HIV Risk Behaviours

Participants discussed their views as to why HIV had spread so widely in the fishing communities and provided certain characteristics or behaviours of fishing community members they believed put them at higher risk for contracting the virus. Participants stated that sexual activity was common element of social interaction at the beaches, leading people to engage in multiple sexual partnerships that could occur concurrently or serially within a short period of time. Jaboya relationships, which have traditionally referred to the mutual support system for financial resources, goods, or services between two fishing community members, may sometimes involve a sexual component, and these relationships were also perceived by participants as another reason why HIV has spread widely in these communities. Commercial sex and low condom use were other sexual behaviours that participants believed contributed to their high risk for HIV.

In addition to these sexual practices, alcohol and drug use and certain cultural practices, like widow inheritance and men not traditionally being circumcised, were also factors in the spread of HIV in these communities. High alcohol consumption and drug use were seen by participants as primary drivers of engaging in risky sexual behaviours: people forget or cannot be bothered to use condoms, have multiple sexual partnerships, or engage in commercial sex due to being under the influence of alcohol and/or drugs. Alcohol was also considered by participants as an obstacle to adhering to HIV treatment if the person is HIV-infected; being intoxicated prevents the person from remembering to take the antiretrovirals every day or from being concerned enough with one's health to take the medication.

Access and Uptake of HIV-related Health Services

Knowledge of HIV prevention measures is high among these communities. Participants knew that HIV testing and counselling was important for knowing one's status and where testing services were offered, while condoms were perceived to be available at the beaches and health facilities. Participants also recognised that male circumcision could reduce a male's risk of contracting HIV. Despite this high level of awareness about HIV prevention measures, there are certain barriers that prevent persons from adopting these behaviours. Fear of knowing one's status, along with testing services being offered at inconvenient times and requiring too much travel, were cited by participants as challenges to going for HIV testing. Participants also expressed concerns about the privacy and confidentiality of testing services. Regarding medical male circumcision, participants provided several reasons why men still chose not to be circumcised: male circumcision is not traditionally part of the culture;

women will not want to have sex with a circumcised male partner because of diminished sexual pleasure; recovery period may mean lost wages from not going to fish; and abstaining from sexual intercourse during the recovery period is too difficult. Participants also stated that having one sexual partner at a time, abstaining from sex, and receiving health education were ways to reduce the risk of getting HIV.

Participants also recognized the importance of seeking care and treatment if one has HIV infection and that HIV medication, if taken daily, could allow an infected person to be healthy and live a long life. However, there were several common reasons provided by participants for why persons with HIV did not adhere to their antiretroviral therapy (ART), including forgetting to do so every day, stopping ART once they felt better, or not having the financial resources to travel to the health facility to refill their ART supply. Fishermen who have HIV experience occupational challenges in taking ART, given the logistics of accessing and carrying ART while they are fishing on the lake, such as their pills being spoilt, finishing their ART supply while on the lake, or not having the privacy to take pills on the boat. Stigma related to HIV in these communities is also an obstacle for accessing and utilizing HIV care and treatment services and ART adherence, according to participants. Despite widespread recognition by community members that HIV is a common problem among the fishing community, HIV-infected persons fear being seen at the health facility, traveling to the health facility, and taking pills, as they believe this would disclose their HIV-positive status; it was perceived that once others were aware of their HIV-positive status, this would lead to negative consequences for their employment opportunities and/or personal relationships.

Conclusion

HIV has had a devastating impact on the health and livelihoods of people in these Lake Victoria fishing communities. Many fishing community members recognize that HIV is a critical health problem facing their communities. While respondents had a high level of knowledge about HIV prevention measures and the life-saving importance of treatment for HIV-infected persons, knowledge did not equate to practising protective behaviours, like condom use and getting HIV tested, or adhering to ART. For fishermen who have HIV, there are unique occupational challenges to ART adherence given their working environments and mobile lifestyles. Issues related to the access and utilization of health facilities, such as the distance to travel to the health facilities, the facilities' hours of operations, and concerns about privacy and confidentiality at the facilities, discourage people from utilising health services. Stigma related to HIV also poses huge barriers to accessing HIV testing, care, and treatment services, and thereby reducing the transmission of HIV in these communities. To reduce the spread of HIV in these fishing communities, HIV prevention, care, and treatment programs must be tailored to fit the schedules and migratory lifestyles of this population. Interventions must build upon the current level of knowledge among the fishing communities and strive to engender the skills and overcome the barriers that will facilitate them to practise protective behaviours against HIV or adhere to ART if HIV-infected. Addressing and reducing stigma related to HIV in this population will be critical for decreasing the burden of HIV in this population.

INTRODUCTION

Increasing attention has been focused on fishermen and others involved in the fishing sector given the high prevalence of HIV within this population. In a cross-country analysis of HIV prevalence among fishermen and/or fishing communities, Kissling *et al.* found in the three African countries analysed (Kenya, Uganda, and Democratic Republic of Congo), HIV prevalence among fishermen or fishing communities, aged 15-49 years, was five to six times higher than the national average prevalence for the same age group; the prevalence in these countries ranged from four to seven percent [1].

There are several factors that make those involved in the fishing industry highly vulnerable to HIV infection. For fishermen, the migratory lifestyle, high levels of alcohol use, younger age, low levels of education, access to daily cash income, and long periods of time away from home have all been identified as factors that contribute to this group's high vulnerability of contracting HIV [1, 2, 3]. The high risk nature of the occupation may also encourage taking risks in their sexual lives, such as unprotected sex and multiple concurrent sexual partners [3].

Women in the fishing industry are likewise at high risk for HIV infection. The roles they occupy are primarily in small-scale trading and processing, which limits their economic earning potential from fishing and makes their livelihoods highly dependent on obtaining fish from the fishermen [4]. As such, these women may engage in high HIV risk behaviours, like transactional sex, to secure fish or other types of support. In a study of 250 fishermen along Lake Victoria in Kisumu, Kenya, two-thirds of the fishermen reported engaging in transactional sex, where they exchanged money or fish for sex [5]. Limited economic means as well as low education levels contribute to these women engaging in high risk sexual practices and increasing their vulnerability to HIV infection.

In Kenya, HIV is of especial concern for the Lake Victoria fishing community population. The prevalence of HIV in these fishing communities has been estimated to be between 21 and 30 per cent [1, 5, 6, 7, 8], while one study found HIV incidence to be as high as four percent among fishermen in Kisumu county [8], which is similar to the rates of new infection found in the Lake Victoria fishing communities in Uganda [9]. This high burden of HIV in the fishing communities may play a significant role in the high HIV prevalence found in the Nyanza region, perhaps contributing up to 25 per cent of all new HIV infections [10]. The HIV prevalence among adults aged 15 to 64 years in this region was 15 per cent in 2012 [11], while four of the five counties within this region had HIV prevalence estimates between 16 and 26 per cent among adults in 2013 [12]. These regional and county prevalence estimates were two to three times higher than the national HIV prevalence of 6% among adults [11, 12]. In recognising the severity of the HIV burden among the Lake Victoria fishing communities, the government of Kenya has identified the fishing community as a vulnerable population that is at high risk for HIV infection in the Kenya AIDS Strategic Framework (KASF) for 2014-2019 [13]. KASF has also prioritised them as a target group for HIV prevention, care, and treatment interventions.

To better understand the perceptions of fishing community members toward the burden and impact of HIV in their communities, as well HIV risk and HIV health services, the National AIDS and STI Control Programme (NASCOP) of the MInistry of Health, in coordination with the Field Epidemiology Society of Kenya (FESK), the University of California, San Francisco, and the U.S. Centers for Disease Control and Prevention (CDC)-Kenya, conducted a qualitative study among fishing community members working or residing on the beaches of Lake Victoria in Kenya. This qualitative study aimed to collect information on the following: roles and responsibilities of fishing community members; their migratory patterns around Lake Victoria; perceptions of the burden and impact of HIV/AIDS in their communities; HIV risk factors; and attitudes toward, access to, and utilization of HIV-related health services.

METHODS

We conducted 25 focus group discussions (FGDs) and 29 key informant interviews (KIIs) across nine beaches in August 2014. There were two to three FGDs and three to four KIIs administered in each study site. The beaches were selected as study sites based on the following categories: beaches that were located on islands or the mainland; the main type of fish found at the beaches – *Omena* (silver cyprinid), Nile perch, or tilapia; beaches that were situated on the north or south side of the lake; and beaches that were rural or "urban" (defined as close to an urban centre). These concepts were selected to ensure that the study sites represented the various characteristics of the beaches along Lake Victoria, as well as the four administrative counties (Siaya, Kisumu, Homa Bay, and Migori) of interest. The nine beaches selected were: Asembo, Bam Got, Chuowe, Ndeda, Nyandiwa, Ogal, Remba, Sena, and Usenge.

The target population for this study was persons involved in the catching, selling, preparing, and buying of fish, such as fishermen, boat owners, fish traders, and fish processors. Those persons who operated businesses at the beach (e.g. restaurants, hotels or shops) and Beach Management Unit (BMU) officials were also included. BMU officials were solely interviewed through KIIs, while other informants were males or females who could provide in-depth information about the activities at the beach. The FGDs were comprised of those involved in fishing activities or worked in businesses based on the beach; they were divided among men only, women only, and in some cases, combined women and men. Study participants were mobilised through the BMU offices and partner organisations that provide HIV-related health services at the beaches- Elizabeth Glaser Pediatric AIDS Foundation (EGPAF), Impact Research and Development Organization (IRDO), International Medical Corps (IMC), and Kenya Red Cross. All participants were 18 years or older and provided informed consent to participate in the study.

Both the FGDs and KIIs were semi-structured interviews, following the study guides (Appendix 1). All interviews were conducted in private areas at the beaches to ensure confidentiality. Research assistants, who were trained on the informed consent process, interviewing techniques, the study tools, and note-taking, administered the interviews and took field notes during the interviews. Interviews were audio-recorded for transcription and translation after

data collection. Once data collection was completed, all interviews were first transcribed from the local language, Dholuo, based on the audio recordings and then translated into English. For quality control, 10 per cent of the translated transcripts were randomly selected and reviewed for accuracy. The translated transcripts were entered into NVivo, version 10 (QSR International, Victoria, Australia) for coding according to the study codebook and analysed for emerging themes. Audio-recordings and transcripts were kept in a secure location and accessible only by designated study staff.

The study protocol was reviewed and approved by the Ethical Review Committee of the Kenya Research Medical Institute; the Committee on Human Research of UCSF; and the Office of the Associate Director of Science of the Center for Global Health at CDC.

KEY FINDINGS

I. Fishing Community Roles, Interactions, and Activities

Fishing Community Roles and Responsibilities

The fishing communities around Lake Victoria comprise a diverse set of roles in order to catch, prepare, and bring the fish to market. Fishermen, who go into the lake to catch fish, are exclusively male. They typically go out in crews of two to five men, depending on the type of fish that is being caught. These crews are hired to work on a boat by a boat owner. Fish brokers and fish traders obtain their fish from the fishermen and may then arrange for the fish to be processed or manage the sale of the fish. There are fish traders who deal locally by taking fish to the market to be sold, and those who come from far to arrange for the transport of fish to factories for sale within Kenya or internationally. Fish brokers and fish traders may be male or female, but those who sell to local markets are often female. The processing and preparation of fish is conducted solely by women. This includes various roles, such as cleaning, de-scaling, drying, smoking, and/or frying fish. Other roles include lorry drivers, taxi drivers, and motorcyclists, as well as women who manage or cook in the *abila* (rest house) where fishermen may stay at the beaches in between times of fishing.

When a fishing boat returns to shore, the fishermen are immediately met on the beach by fish brokers and traders, who purchase fish and remove it from the boats. Fish traders either purchase their fish directly from the boats on the beach, or they purchase fish at the *banda*, a large open-air structure near the shore where fish is brought to be weighed and sold. From the *banda*, some fish traders take fish to sell at local markets, while others package fish to send to Kisumu or take fish to factories for packing and transport to further areas.

> *"For traders, it is [the] banda that brings them together, both established and small traders come to this place. Some traders pick fish here and sell them here and that is it. There are others who pick fish, put them in sacks and label them before they can load them on motorbikes. They are then ferried to the bus stop where they are transported to Kisumu. Some may also pick fish and sell them in local markets, so markets where they sell are different." – **male study participant***

Following the sale of the fish, fishermen often find a place on the shore to relax, or hang out at the banda where fish is sold. If they have other work that they need to accomplish, they may dedicate themselves to their work in the time they have available. If fishermen have houses in the village, they may go home, or for those that do not, they may go to the *abila*. For fishermen looking to entertain themselves, bars, alcohol dens, and pubs are popular, as are video houses, shopping centres, hotels for tea, and places where soda is sold. Other places where fishermen may go when they are not fishing in the lake include places to gamble, dance clubs, places where they can smoke bhang (marijuana), places to watch football, or church.

Similarly, when fish traders are not selling fish, they often attend to their chores or go home. Some female fish traders are involved in 'merry go rounds,' or microfinance community groups, with other women and may go to meetings for these groups. Other places where fish traders may go include bars, places where they can watch football, play pool, or dance, video houses, and church.

Mobility

Fishing in Lake Victoria necessitates a high level of mobility. When fish are scarce in the usual fishing areas for the boat, the fishing crew is forced to move to another location to find fish. After making a catch, the boat may dock at other beaches. Since fishermen have certain customers with whom they are accustomed to dealing with, these fish brokers and traders often follow fishermen to other beaches to obtain fish.

> *"Migration of fishermen prompts migration of both boat owners and traders. If those who used to work for me, as fishermen, migrate because of scarcity of fish at the usual beach, I will have to look for them. I will follow them to the latter place where the catch is deemed to be more. If I also had a trader whom I used to give fish supplies, I will call her and inform her of our new location. She will also have to follow me since she was my customer." – **female study participant***

This guarantees that the brokers and traders get access to fish and ensures that the fishermen have customers wherever they land.

> *"Traders are people who walk in search of fish; their job demands that they follow the fishermen wherever they move. If they come to learn that fish is available at the other beach, they'll have to move there. They cannot stay at this point when there is not much for them to do. Their work is not to fish; rather they collect what the fishermen have brought to the beach and supply to the market. This explains why they have to move to the other beach where the fishermen have moved to in order to find fish and supply to the market." – **male study participant***

Fishermen may also migrate across borders into the waters of Uganda or Tanzania to follow the fish. Certain fish breed on the Kenyan side of the lake and then move toward Uganda and

Tanzania as they mature, according to respondents. Given the restrictions on catching under-sized fish, fishermen migrate to these others parts of the lake to catch the mature-sized fish. Study participants expressed that this international migration can be challenging because they can be arrested or killed for fishing in non-Kenyan waters. Kenyan fishermen are not allowed to land at Ugandan or Tanzanian beaches and must return to Kenya to dock their boats and sell their fish.

II. Burden and Impact of HIV on the Fishing Communities

HIV is a common disease in these fishing communities. Study participants stated that a large proportion of their communities are infected with HIV. As one female participant expressed:

> *"AIDS is paramount, its everywhere, when you find like a group like we are now 15 here, you will find that 9 people have it, eeeh it's not a lie that when you start testing people one by one as they leave that door you will find that it is true." - **female study participant***

Participants also expressed that HIV is a more serious health problem in their communities compared to other diseases. This was because many people had died from HIV/AIDS, and though mortality from HIV/AIDS has declined with the increased availability of HIV treatment, some people still perceive having HIV to be a death sentence even with treatment.

> *"Just like my colleagues have said, HIV is a disease that kills people and it is the most burden compared to other diseases. It kills because it has infected you then you must know you will die even if you take drugs sometimes you may forget to take drugs, and you know that you can die any time."- **male study participant***

The impact of HIV to the infected person and the family unit was described by participants as devastating. For those who are infected, participants stated that HIV made their bodies weak and interfered with their ability to work well because of decreased strength, the side effects from the medicine, and not being able to work long hours. As such, people with HIV made fewer wages, and this negatively affected the household income. This lost income, in addition to the financial resources required for medical care, often impoverished families. The death of primary household wage earners or caretakers due to HIV has led many wives to become widows and many children to become orphans. Participants explained that this vulnerability due to poverty led women to engage in high risk behaviours for HIV to earn money, while children who lost their parents or primary caretakers leave school to catch or sell fish to support themselves and their families. For these reasons, HIV has had debilitating generational consequences on these fishing communities.

*"The burden that I see that the HIV virus and the HIV/ AIDS is bringing to the fishing community is that they do not care about their lives and so they go and engage in sex after they have taken those bitter things [alcohol or drugs] that we were talking about. If they have entered into these things, you find that someone does not care and even if it is [that] with drug [for HIV], his life cannot last for a longer time and if it cannot last longer…you know if a parent has died, it means that even those children of his cannot have a smooth life. So you find that this life interferes with the family and even those children remain there when they are still young, even school they cannot complete. They will also follow suit, what their father did, they will say that if I have reached this stage, and there is no one who can take me to make me move forward, let me also go into fishing that my father was doing. So that is the burden that it brings to the fishing community." – **male study participant***

III. HIV Risk Behaviours

Participants discussed their views as to why HIV had spread so widely in the fishing communities and provided certain characteristics or behaviours that they believed put people in their communtiies at higher risk for contracting the virus. Sexual practices, alcohol and drug use, and certain cultural traditions in these communities were frequently associated with HIV risk, and this risk was further compounded by their migratory lifestyles to various beaches along the lake.

SEXUAL BEHAVIOURS AND PRACTICES

Respondents described that sexual activity was a major driver of social interaction in beach communities and this (desire for sex) leads people to engage in multiple sexual partnerships that may sometimes occur within a short period of time or concurrently. Not having a sexual partner is viewed as strange or unusual.

*"And you'll not find…if you find someone who walks about without a lover…leave alone jaboya, they call them atoti [reference to sexual partner]. If you come across a man who does not have atoti around this place, everybody would be asking what kind of person he is. Each and every person must have his own what…his own atoti." – **male study participant***

Participants stated that sexual partnerships occur between all the different groups found at the beach, such as between fishermen and fisher traders, brokers, or processors (female); boat owners (male) and fish traders, brokers, or processors (female); and boat owners (female) and fishermen.

Jaboya Relationships Involving Sex

Jaboya relationships that involve sex are perceived as one reason for why HIV has spread so widely in these communities. Traditionally, *jaboya* is a term used to describe a person who

provides monetary resources, goods, or services to fishermen or boat owners. This person may be a male or a female. In return, the fishermen or boat owners will guarantee fish or other support to this person. Given the irregularity of income from fishing, this system of mutual support has been an important element of the interpersonal relationships in these communities. A common scenario of *jaboya* on the beaches is the relationship between a female fish trader and a male boat owner, whereby the fish trader will provide the resources for fishing equipment (such as nets or lights) or money for boat repairs in return for a guaranteed supply of fish from the boat owner. She may be prioritised to receive fish first once the boat lands, be given the best-sized fish, or receive a discounted rate on the fish provided. Other scenarios involve female fish traders and fishermen, female shopkeepers and fishermen, or female boat owners and fishermen. As one participant described:

> *"The jaboya can also be that he is a jaboya for a boat, sometimes he has a hotel. I have my customers that I agree that he is the jaboya and he drinks from my hotel, they can be my jaboya for fish because they are my customers, in other words they drink my tea me as the owner of the hotel. So they take my tea and if I go to the lake shore they look at me as their jaboya. I am their jaboya for tea and they are my jaboya for fish. So jaboya is just a Luo word that was put, jaboya is just a way of getting fish.Eeee….so he can be the amali [someone who brings back fish from the lake] who goes to the lake, or someone who goes to the lake. At times he can give me 50 shillings, I buy cigarettes, and I can give him. So the following day if I hang with my basin next to the boat where even if the fish were few, he must remember that I gave him some cigarettes that helped him remove some cold [stay warm] in the lake there, he drops me some fish. So that is how this luo word for boya comes in. That one that goes deep. I think I have made it clear."* - ***female study participant***

Participants expressed that the meaning and practice of *jaboya* has altered over time to include a sexual component. In this context, jaboya can refer to a female who not only provides money or goods (such as cigarettes or food) to the fishermen or boat owners in return for fish but is also a lover, or sexual partner, of the male she supports. Additionally, *jaboya* can signify a male, usually younger in age, who is employed as a fisherman by an older female boat owner and is involved in a sexual affair with this woman. It is possible for one's *jaboya* to be one's spouse or for each partner to have a spouse outside of the *jaboya* partner.

> *"You always see that when I come with fish, I will always give that to my jaboya. Sometimes you could be giving this woman, because sometimes you don't have money, you didn't go fishing. But she will give you even 50 shillings that you are going to do what, to use to take tea. That your jaboya sometimes she is a lady who is still young. This woman is your friend in the flesh [sexual partner]. Such that when you come from that end, you know pretty well that my lady from Gem [nearby*

town], you know that is my jaboya. So when you come with your fish, "my lady here is the fish for you, please take it." Meaning that she is your jaboya in the flesh or in what way, in business. You have combined two things. So there are different forms of boya." – male study participant

"They also take young men as jaboya. When they see young men who have arrived at the beach, like you, she would rush and ask you whether you need a job. If you want job, just come we work, but then you work with her in many ways. If she finds that you are good in the act [of sex]…you know you are a young man and she is an old woman who probably her husband died long ago and then she got some money to come to the beach. You may be picked as the supervisor of the boats, so you don't have to struggle going out at night in the cold. With that you've just become her jaboya. Even your kinsmen may look for you in vain, only for you to go back as a corpse. They are many along these beaches. A man comes and a woman has made him jaboya because she has much money. So the issue of jaboya is one you can never exhaust, it is rampant over here" –male study participant

This study found that modern *jaboya* relationships between women and men are complex support relationships that may involve love and affection while also maintaining the transactional element. Participants in some communities described how a *jaboya* relationship could develop into that of a boyfriend and girlfriend. In some circumstances, the relationship is driven by the dependency on the exchange of money, goods, and favours.

"The rule of jaboya even if he brings bad fish or omena you will take it and after that he sleeps with you." – female study participant

In other situations, the sexual, emotional component is the primary factor for maintaining the relationship. *Jaboya* can be used to refer to the female or male with whom one has sex, and the issue of support with fish or money is like a favour or gift because of being lovers. As one female participant declared:

"Jaboya is your boyfriend that you have sex with, the issue of fish is just a by the way but all in all, he is your lover." – female study participant

Based on the participant interviews, the duration of *jaboya* relationships is variable; they can last for a short season or they can continue for a long period of time. However, they do not seem to be "one-off" instances of sex being given or received for goods or services. These relationships end when one partner decides to look elsewhere for a partner, either because the level of support (i.e. fish) has reduced so the recipient must search for another provider or because the provider has chosen to support another person. Reasons for supporting a new person may stem from a physical and sexual attraction to that new person, where the support is given to initiate a new *jaboya* relationship with that person. As such, once the support element of the *jaboya* relationship ends, the sexual relationship halts as well, and vice versa.

Though people are aware of the high burden of HIV in their communities, discussing HIV status with their *jaboya* sexual partners is not commonly done. Participants explained that when people urgently require support, usually fish or money, they then may engage in sexual intercourse with their *jaboya* partner to get this support. They may be concerned about contracting HIV from their partner, but the greater worry is obtaining fish to prepare or sell or money for expenses. This need for money or fish may also supersede people's desire to use condoms, especially if more money or fish can be gained without them, or the desire to know the partner's status before having sex:

> *"I would like to add a little to that, most of us when dealing with jaboya they don't even go for test, they just have sex with no protection, they are only interested that they get fish and omena, that is all they are interested in''- **female study participant***

This is especially true for the women in these communities, where the money may be required for feeding their children or paying for other household expenses. Female participants in many of the interviews expressed the hardship of financially supporting their families, especially if their husbands had died or were away fishing, and, having a *jaboya* partner who guaranteed a supply of fish for them was a therefore considered necessity for their livelihoods.

> *"Maybe I was married in Asembo [another beach on Lake Victoria], then I came here and for a whole week I was going to the lake and coming back with nothing. Then I can ask you that, can I get the means of getting omena from this beach, because I'm dying out of hunger with my children, then you are told that if you don't have someone to fish for you, you will not get omena. This jaboya, then I feel like I should also look for a man, I'll look for him through all means…" – **female study participant***

Commercial Sex

Apart from the ongoing sexual relationships that occur in these communities, commercial sex, or the buying or selling of sex for money, is widespread, according to respondents. It is usually the fishermen who solicit sex from female sex workers, as they have the money to do so. Participants explained that if the catch that day has been plentiful, fishermen will have large sums of money to spend. This money may then be used to buy sex, which is seen as a way to unwind after a laborious period of fishing. Female sex workers may be residents of the beaches or nearby towns, or they may have come from as far as Nairobi or Mombasa. These women travel long distances because they know that the demand for sex is high and that fishermen have the means to pay, especially during the high seasons of fishing. During these times, female sex workers may earn up to Ksh 500 to 1,000 per client. They may take up employment at the local bars or hotels on the beaches to establish their client base and operate from there, or they may invite their customers to their homes on the beaches.

"Here in the beach we have people who practise commercial sex though not registered but they are here. They know that there is fish in such a place so when someone comes from the lake, will come look for him. They are called angang, they are here. You find that she rents a house within the beach so the commercial sex that she does is what she uses to pay her rent. So when she sees you in a certain boat that landed well with a lot of fish then she knows you have money. She will look for a way to come to you and you will end up going to her house. You will hear a fisherman say that today I'm just going to this angang's house and we also have bars here in the beach that we hire. We allow them to do business here so these bars bring these women to make their business boom so they try to bring ladies. Like you find that in a month they bring 10 ladies and again the next month 10 girls." – female study participant

Women who reside in these communities and are engaged in fishing-related activities may also exchange sex for money. They may not consider themselves as sex workers, as it is not their primary way to earn income but a temporary means to quickly obtain money that is immediately needed. The man is usually known to the woman, resides at the same beach, and is likewise involved in fishing activities.

Low Condom Use

While participants expressed a high level of awareness about the protection that condoms offer against sexually transmitted infections (STIs) and HIV, condom use seems to be low or not preferred in these communities. Diminished sexual pleasure was a primary reason provided by participants at the various study sites for not using condoms. As one participant stated:

*"It means you can't have sex when someone is putting on a condom, then you say that you are now feeling the sweetness, they say that you go skin onto skin, is when he gets to know he actually slept with a person and he releases." - **male study participant***

Fishing community members perceived that unless it was *"nyama kwa nyama"* (or flesh to flesh), it was not actually sexual intercourse; using condoms during sex was therefore undesirable, despite knowing that condoms protect against HIV transmission.

Having sex while under the influence of alcohol or bhang was also a barrier to condom use. After taking alcohol, people tend to forget about using condoms entirely or choose to not be concerned about the risks of unprotected sex. Participants also expressed that in transactional or commercial sexual relationships, people tend to offer or receive more money if condoms are not used because of the sexual partner's preference. As one female participant expressed:

*"Sometime back there used to be a certain man here who used to say that if you sleep with him without a condom, you get 1000 Kshs and without a condom you get 500 shillings, so that tells you that sometime you may wish for 1000 Kshs, because you see it as too much thus risking your life so as to get 1000 Kshs, so you see these people are the same." – **female study participant***

Other reasons for not using condoms provided by respondents include low or no perception of risk for contracting HIV based on the partner's physical appearance and the building of trust as the relationship progresses. Participants explained that people sometimes assume that their partner does not have HIV because the person looks healthy and does not appear to be ill. They therefore perceive little or no risk for getting infected with HIV and do not feel it necessary to use condoms. Participants also voiced how people tend to believe that using condoms are important during the first few sexual encounters, but this attitude changes as the relationship progresses. As such, condom use in ongoing sexual relationships is not typical.

*"He uses the Trust [brand of condom] on the first sexual encounter and as the friendship grows, he stops using condoms. He now sees [it] is ok, and does it without [condom]". – **female study participant***

ALCOHOL AND DRUG USE

High alcohol consumption and drug use were pervasive among these fishing community populations. Participants conveyed that alcohol was consumed by both men and women, though youth (those aged 18 to 25 years) and men, specifically fishermen, tended to imbibe high quantities of alcohol. The types of alcohol that were normally consumed were the locally brewed beer and spirits, particularly *changa'a* and *rwata rwata*. Youth and fishermen were also considered the main groups that used drugs; the most common drugs mentioned were bhang (marijuana) and kuber.

Participants explained that fishermen frequently used drugs, primarily bhang, and cigarettes while fishing in the lake. It was believed that they give them energy to work and provide warmth, preventing them from feeling the low temperatures and strong winds. Participants also stated that the alcohol and bhang boost the fishermen's morale and allow them to brave the strong waves and other dangers of the lake.

*"What I know about the usage of these drugs and the people that use them. Mostly it is the marijuana that is used because they say that it gives them the courage to fish due to the funny things that are associated with the lake. This marijuana boosts your courage to sail through the lake despite the funny things [winds] happening in the lake. They say that okinyal dhiye gi wiyi lilo [you cannot sail through this episode of funny winds in the lake with a sober mind]." – **male study participant***

Alcohol is most often consumed while the fishermen and boat crew are at the beaches, and not as often or as much while fishing in the lake. The BMU has established strict rules that prohibit fishermen and boat crew members from going fishing if they are intoxicated to prevent against accidental drownings. While they are on shore, male fishing community members consume large amounts of alcoholic beverages. Participants indicated that drinking alcohol is a common way to unwind after fishing in the lake and is an important part of socialising with others, including *jaboya* relationships. Participants reported that a good proportion of the fishermen's income from their daily catch is spent on alcohol.

Many of the study participants viewed high alcohol consumption and drug use as a key contributor to the spread of HIV within their communities. People described alcohol and drugs as primary drivers of engaging in risky sexual behaviours; people forget or cannot be bothered to use condoms (as described above), have multiple sexual partnerships, or engage in commercial sex due while under the influence of alcohol and/or drugs.

"Telling the truth, most of the fishermen take a lot of bhang and alcohol, when they are already drunk, they don't think of using a condom." – female study participant

*"Those residing at the beach depend a lot on alcohol, let me say drugs. They reason that drugs give them the strength and morale to work. However, the drugs only drive them to sexual immorality, and prompt them to do what they shouldn't have done at that particular time." - **female study participant***

In addition to increasing their vulnerability to contracting HIV, alcohol was considered by participants as an obstacle to adhering to HIV treatment if the person is HIV-infected. Being intoxicated prevents the fishermen from taking his antiretroviral (ARV) drugs every day, either because he forgets or does not care to do so. As one participant described:

*"The burden that they can see is that after they have been infected, it is the issue of taking the ARVs every day. Sometimes he sees that he is busy and his time for drugs is passing. Sometimes he is a drunkard and he is not interested on the issues of the drug. So that is the burden that someone can see on taking drugs every day." – **female study participant***

CULTURAL PRACTICES

Widow inheritance and the practice of not circumcising males were two cultural practices mentioned by participants that put people at greater risk for contracting HIV. Widow inheritance is the practice by which a widow is inherited by a male, traditionally a male member of her husband's family, after her husband's death, and this man is then responsible for providing for her and her children. This practice is not specific to the fishing communities but common in the region bordering Lake Victoria. At times, in the present interpretation of this tradition, some people believe that sexual intercourse is required between the widow and the inheritor, who may be from outside the family, for the widow to re-join society after her husband's death. This practice can occur between younger widows and older men or older widows and younger men. Participants expressed that this practice sometimes enables the transmission of HIV because the sexual requirement of the inheritance must be completed regardless of whether the persons are HIV-infected or have unknown status.

> *"Our social cultural behaviour the way I see it is that the way in the Luo community, if your husband dies then you must be inherited. So some you can feel so low, because you don't know the person who is inheriting you, the whereabouts of his HIV status, it some it forces that he has to inherit you even if he is infected he has to inherit you." – **female study participant***

Furthermore, the use of condoms during sexual intercourse for widow inheritance may be prohibited or rejected. Some people believe that if sex is not done "skin to skin," the cleansing of the widow has not been properly done, and this may bring misfortune to the widow's family. Consequently, condoms are not used, leaving both persons susceptible to getting infected.

> *"The norm of the Luo culture dictates that for you to be cleansed from the death spirit of your husband you take one week, so you cleanse all the bad spirit in your home. You must have unprotected sex, skin to skin, and nothing like Trust [brand of condom]. That's why HIV/AIDS spread like bush fire, because customs does not allow you to go with a condom, when you husband dies. And maybe you want to help your children, so it will force to take another man to inherit you to cleanse you, and if these man uses Trust condom during the intercourse that shows you haven't cleansed yourself, it forces that you must have lived [had sex without a condom] to cleanse yourself and your home." – **female study participant***

Another cultural practice that contributes to the HIV risk profile of fishing community members is that men in the respondent communities are not traditionally circumcised. Male circumcision can reduce a man's risk of HIV infection, and voluntary medical male circumcision (VMMC) programs have been established in these areas to encourage men to get circumcised to decrease their chances of getting HIV. However, many men in these communities have not gone to be circumcised because it is not part of their tradition to do so. As one participant stated,

*"No, in terms of circumcision many people other people don't access to it during the days of circumcision to them they believe in their culture." - **male study participant***

The issues around the uptake of and barriers to medical male circumcision are discussed in further detail in the subsequent section.

IV. Access and Uptake of HIV-related Health Services

Overall, the participants displayed a high level of awareness of HIV prevention measures, as well as the importance of antiretroviral therapy (ART) for treating one's HIV infection. This section details the attitudes and perceptions of the participants toward the HIV health services in their communities.

HIV PREVENTION

HIV Testing and Counselling

With regard to HIV testing, participants across all the study sites were aware of the importance of getting tested to know their HIV status. In some beaches, participants felt that HIV testing and counselling was the most commonly available service at the beach, whether through testing campaigns or home-based testing and counselling. Participants also knew that HIV testing was available at health facilities, and that HIV testing was a service provided free of charge. Participants believed that the majority of persons in their communities had tested for HIV at least one time, while women were more likely to get tested compared to men, as well as seek out health services in general. However, testing modalities that were closer in distance to the beaches or on the beaches and offered at various times seem to provide the most convenience for utilization. For example, participants expressed that HIV testing and counselling services should be available more than once a week at the beaches and not only offered in the mornings when fishermen and boat crew members are just returning from the lake and too tired to go for testing. Participants also felt that the counselling portion was lacking when they went for testing, either because counseling was not done at all or because it was not thoroughly done.

Despite the high level of knowledge about the importance of HIV testing and counselling, there are several barriers that prevent people in the respondent communities from getting tested. Fear of knowing one's status was a major barrier to getting tested for HIV. This fear was specifically in regard to the perception that HIV still means immediate poor health and death, loss of income, and stigmatization from others in the community. There were also concerns about confidentiality and privacy of testing for HIV at the Voluntary Counselling and Testing (VCT) sites, such as health facilities or even mobile testing at the beaches, due to the stigma against HIV in their communities. People feared being seen traveling to and at the health facilities and that this would automatically disclose to others that they were HIV-infected. As expressed by one participant:

"So fear seems to be there, the kind of people you want to meet on the way, who wants to see you at the gate, the people who are maybe the women who cleans, who went to the clinics once, they have seen you go into that VCT room. He just sees, even when you haven't been tested or tested, but he doesn't know your result which he is not even concerned about. And he says that so and so is taking the drugs so people fear, so people fear going to such places." – ***male study participant***

Some participants also mentioned distrust of health providers in maintaining confidentiality about who has gone for testing and who is HIV-positive as a barrier to HIV testing.

"[I] think something like VCT we have here, God helped us we have a hospital here. If you go there, they measure HIV, something for the sickness of TB is also measured for free... Now these are there but mostly the people fear, mostly the fishing community and fishermen, fear going to the hospital, because they know if they go there, they will be told to go to the VCT. He is going to be tested and this is what they do not want. " – ***female study participant***

Medical Male Circumcision

Participants were aware that male circumcision was a key component of HIV prevention and that being circumcised could reduce a man's risk of contracting HIV by 60%. In recent years, voluntary medical male circumcision (VMMC) campaigns have been established to educate these communities on the importance of male circumcision and to increase the percentage of men who are circumcised. However, despite knowing the benefits of male circumcision for HIV prevention, participants expressed several reasons why men still chose not to be circumcised: male circumcision is not traditionally part of the culture (as described previously); women will not want to have sex with a circumcised male partner because of diminished sexual pleasure; recovery period may mean lost wages from not going to fish; and abstaining from sexual intercourse during the recovery period is too difficult. Given these reasons, participants felt that it was much easier for boys to be circumcised, rather than men of older age.

*"Sometimes back they brought us VMMC, and a few people went, they told us that it can reduce HIV infection by sixty percent. Many people did not want to go and get circumcised due to the pain and because it will take you three months without having sexual relationship with a woman so some people were afraid. Those who had high sexual libido did not want to go because it may force them to stay for long without having sex with their wives." –***male study participant***

*"There is a very big difference, that people fear being operated, because when you have been operated, it stops you from doing your job with our job which is in the cold , and it is our source of income ,and so when I am operated, I am very sure that you cannot go to the lake because during that time you had pain…that is why you see most schools, most of [those in] the primary schools, can easily go because they are still under the care of their parents." –**male study participant***

However, some participants did relay that they had seen men who had been "cut" and returned to work shortly after the operation.

Condom Access

As previously described, most study participants knew that condoms provide protection against contracting HIV. Participants expressed that condoms were generally available on the beaches, either through condom dispensers at the BMU office, community health workers, or at the health facilities. However, participants expressed that some people felt embarrassed about being seen taking condoms from the public dispensers and would only go at night to get them or not at all. Other access challenges included dispensers not being stocked or erratic condom supply, where condoms would be widely available for free one month and then only available for purchase at the shops the next month.

*"What is currently happening is that there are a lot of interventions. During piloting, organizations will try to be frequent. They want to meet their target. Of late, we have a challenge because if people were used to it, you cannot control. They were used to getting condoms free of charge. If you visit the three dispensaries we have around, none of them is loaded. The fisherman has spent his money on a woman. He will forget about the condom. You will tell this person to get a condom at 100 shillings but he will prefer to do it without protection. They know it at the back of their minds but I want to call it negligence. They don't protect themselves from the virus." - **male study participant***

Participants also stated that people sometimes do not use condoms because the shops that sell condoms are not open at convenient times (i.e. evening).

*"You find that most people don't use condoms, because where we are the shops are closed earlier and the ladies that practise prostitution do it late when the shops are closed. Sometimes the hotels are shut down and so you can't find condom and in the lodgings there are no Trust [brand of condoms] so they will just do it like that." – **male study participant***

Other HIV Prevention Methods

The study found that participants had a solid understanding of the various HIV prevention measures. Participants knew that having one sexual partner at a time and abstaining from sex

were additional ways to protect against HIV infection. Not sharing razors, sharps, and needles and ensuring that blood transfusions are examined for HIV were also raised as important methods of HIV prevention. Participants also considered health education as a critical component of HIV prevention, especially parents discussing HIV with their children. As one participant expressed:

> *"It is just a matter of being open and free, after you are open with them, and even if you have older children you just need to teach them on HIV, and teach the things that they can use to protect themselves like the condom, this will make him protect his life." - **male study participant***

HIV CARE AND TREATMENT

Similar to HIV prevention measures, knowledge about the importance of seeking care and treatment for HIV infection was high among the fishing community members interviewed. Participants knew that medication was available to treat HIV, and if taken every day, this medication could allow an HIV-infected person to be healthy and live a long life. Several participants remarked how they had observed the life-saving effects of anti-retroviral therapy (ART) among their beach community members, whereby people who were ill and thin and presumably had HIV now appeared healthy and strong after taking ART.

Participants cited that adherence to ART, or taking the pills every day, was a major challenge for both men and women. Common reasons discussed for why people did not adhere to ART were forgetting to do so every day and stopping ART once they felt better. Participants expressed that it was very burdensome to swallow a pill each day; consequently, once one feels healthier, that person will stop taking ART. As one participant expressed:

> *"Sometimes I fear, sometimes swallowing the drug is not easy for me, I might go and start taking them but when they get finished I stop, I feel I am cured, am well. Later after defaulting the disease comes back again and so for you to again go back to the doctor for you to start again following how he/she given me the one I had left taking. I should not stop medication and that is why I start again feeling sick, so that is fear." – **female study participant***

Lack of financial resources was also given as a reason for non-adherence. Money is needed to travel to the health facility to refill their ART supply and to purchase food, which HIV-infected persons are told to take with their medication. As such, when money is limited, HIV-infected persons will delay going to the health facility or will not take ART that day or period when food is scarce.

"Here, we are talking about fishermen. Everyone looks down upon fishermen. This is a casual worker who earns per day. Even AIDS looks down upon these people. They easily die of AIDS. You can go to the VCT and then think that you are strong enough to do anything because you are on drugs. However, the disease will weaken this person. Once weak, you cannot go there to earn a living. But there are those who work. Some stay in Nairobi. They will take the drugs and lead a healthy life. But the fisherman cannot use the drugs and survive on fingerlings [small fish]. People do say that you need to take the drugs and eat chicken as well." – ***male study participant***

"But now, I have been tested and found to be infected, these people don't go for the drugs. They just see that, the time he wants to waste going to the hospital, he doesn't agree. Maybe he doesn't have money…this happens because of poverty because when he doesn't take his time to go to Sindo [nearby town with health facility] and he only came with 50 shillings from the lake, so he feels that instead he uses that money to go to Sindo, he uses this money with his jaboya to buy quarter kilo of sugar and food. So all these happens because of poverty, testing we have been tested, everything the government has done and NGOs have also done their best that I think everyone has known his/her status but we don't take action because of poverty, he doesn't have money." – ***male study participant***

Fishermen experience additional challenges given the logistics of accessing and carrying ART with them while they are fishing. When the fishermen are out on the lake, their pills may come into contact with water and then get spoilt. Fishermen may also finish their supply of ART if they stay longer than planned on the lake, or they may not have time to take their supply with them as they may depart for the lake in a rush. In these situations, some participants said there were no means available to get the ART to them while they in the lake. Fishermen may also migrate to other beaches in pursuit of fish, and these beaches may be far from the health clinic where they access their HIV care and treatment.

"The burden we get as the fishermen is that we take the ARV's daily and we as fishermen we go far and even forget that you were to take the pills. Even at times I can be in Tanzania so I will exhaust the pills I had left and when they are through I won't continue medication, what is burdening us is that the pills have to be taken daily." – ***male study participant***

However, some fishermen reported that they were able to make arrangements with the health facility to get a larger supply of ART. And should that supply run out or be spoilt, a yellow card issued by their health facility with treatment information would enable them to receive ART from other health centres in that network.

"Before we go to fish at distant places, I may go to that dispensary and inform them that I would be leaving the beach for a given period of time. So they'll give me drugs that would last for the period I would be away. Just in case something happens, I'll be walking with the yellow card. With it I can be given drugs at any health centre wherever I go." - ***male study participant***

Stigma associated with being HIV-infected was an obstacle for accessing HIV care and treatment services, as well as for ART adherence. Despite widespread recognition by community members that HIV is a common problem among the fishing community, HIV-infected persons fear being seen at the health facility, and even traveling to the facility, as this would disclose their HIV-positive status. As a result, HIV-infected persons will travel to farther health facilities to seek HIV care and treatment services so they will not be recognized by others in their communities. This increases the time and costs of seeking health services.

"Let me add something on taking ARVs that it is as a result of shame that his friend may spot him when he goes to pick the drugs. So he feels ashamed. So even if the drugs can run out for him and he has spotted his friend around there still he won't go. That is the burden associated with it." – ***female study participant***

Stigma was also a reason provided by study participants for not taking ART or not taking ART every day. Those with HIV fear being seen taking pills as it would disclose their HIV-positive status and result in negative consequences, such as loss of employment or personal relationships. Participants said that this fear was especially challenging for fishermen to adhere to ART while on the lake, as boats offer little or no privacy to take ART. As one participant described:

"We are all sick but we live like those who are not infected because I'm using the ART and the other person is also using them, but I will be afraid to use them in the presence of this partner because he will realize that I am on drugs, the other person will also be afraid to take his drugs that I will see him, then we end up not taking the drugs at all, this is the main burden of this disease." - ***male study participant***

V. Burden of Sexually Transmitted Infections and Access to Treatment

Sexually transmitted infections (STIs) were also viewed as a critical health issue facing the fishing communities, specifically syphilis and gonorrhoea. In some interviews, participants expressed that STIs were more of burden than HIV in their communities because treatment drugs for STIs alone was not as easily accessed as ART or treatment services were difficult to access by those who do not have HIV, since STI treatment is provided as part of the package of care for HIV-infected persons. As one participant stated:

*"So you find that its treatment has not been advanced. The people who are HIV positive are the ones who are given special attention with regards to syphilis. But if you go there complaining of diarrhoea then you are likely to receive treatment rather if you go to the hospital complaining about syphilis, you asked to go to Sindo [nearby town with health facility] yah." – **female study participant***

Several participants also expressed that they thought gonorrhea and syphilis to be more serious than HIV because they perceived that these STIs were incurable, could not be treated, or were too difficult to treat.

*"I see HIV...I think it is common but the one which is a great challenge to the community that makes them not to rest is gonorrhoea because I heard that it is not curable. I hear once it has affected you it doesn't heal." – **female study participant***

CONCLUSION

HIV has had a devastating impact on the health and livelihoods of people in these Lake Victoria fishing communities. Many fishing community members recognize that HIV is a critical health problem facing their communities. While respondents presented a high level of awareness about HIV prevention measures and the life-saving importance of treatment for HIV-infected persons, knowledge did not equate to practising these behaviours. Misconceptions, lifestyle characteristics, and HIV-related stigma continue to pose ongoing challenges to adopting protective behaviours against HIV, such as condom use and testing for HIV. For those who are HIV-infected, stigma is a significant barrier to initiating care and treatment and adhering to ART, in addition to lack of financial resources to travel to health facilities or follow their care and treatment regimens. There are also unique occupational challenges for fishermen with HIV to adhere to HIV treatment given their working environments and mobile lifestyles. Additionally, issues related to the access and utilization of health facilities, such as the distance to travel
to the health facilities, the facilities' hours of operations, and concerns about privacy and confidentiality at the facilities discourage people from utilizing health services.
To reduce the spread of HIV in these fishing communities, HIV prevention and treatment programs must be tailored to fit the schedules and migratory lifestyles of this population. HIV prevention interventions must be designed to build upon the current level of knowledge among the fishing communities and strive to engender the skills and overcome the barriers that will facilitate them to adopt and practise HIV protective behaviours. Prevention interventions aimed to increase condom use, decrease concurrent sexual relationships, increase and transform negative gender conceptions have a critical role in halting the spread of HIV and were welcomed by these communities. HIV treatment for those who are infected is also essential in reducing HIV transmission, and thereby new infections, in this population. Targeted strategies are needed to facilitate

initiation of HIV care and treatment and strengthen ART adherence within their occupational and lifestyle contexts. Health facilities serving these communities must also review their systems and emphasize the importance of privacy and confidentiality with service providers to encourage utilization of health facility-based services. Lastly, addressing and reducing HIV-related stigma in these communities is of utmost importance for decreasing the prevalence and incidence of HIV in this population.

REFERENCES

1. Kissling, E., *et al.,* Fisherfolk are among groups most at risk of HIV: cross-country analysis of prevalence and numbers infected. *AIDS*, 2005. **19**(17): p. 1939-46.

2. Gordon, A., *HIV/AIDS in the Fisheries Sector in Africa. 2005*, World Fish Center: Cairo, Egypt.

3. Allison, E.H., Seeley, J.A., HIV and AIDS among fisherfolk: a threat to 'responsible fisheries'? *Fish and Fisheries*, 2004. 5: p. 215-234.

4. Bene, C., Merten, S. (2008). "Women and Fish-for-Sex: Transactional Sex, HIV/AIDS and Gender in African Fisheries." *World Development* **36**(5): 875-899.

5. Kwena, Z. A., E. A. Bukusi, *et al.* (2010). "Prevalence and risk factors for sexually transmitted infections in a high-risk occupational group: the case of fishermen along Lake Victoria in Kisumu, Kenya." *Int J STD AIDS* **21**(10): 708-713.

6. Field Epidemiology and Laboratory Programme Alumni Association (FELTPAA), *HIV and AIDS Baseline Sero-Behavioural Study in Fisheries Sector in the Lake Victoria Basin, Kenya*. 2010: Nairobi.

7. Kwena, Z. A., C. S. Camlin, *et al.* (2013). "Short-term mobility and risk of HIV infection among married couples in the fishing communities along Lake Victoria, Kenya." *PLoS One* **8**(1): e54523.

8. Ondondo, R. O., Ng'ang'a, Z. W., *et al.* (2014). "Prevalence and incidence of HIV infection among fishermen along Lake Victoria beaches in Kisumu County, Kenya." *World Journal of AIDS* **4**: 219-231.

9. Seeley, J., J. Nakiyingi, *et al.* (2012). "High HIV incidence and socio-behavioral risk patters in fishing communities on the shores of Lake Victoria, Uganda." *Sex Transm Dis* **39**(6): 433-439.

10. National AIDS Control Council, *Kenya Analysis of HIV Prevention Response and Modes of HIV Transmission Study*. 2009, Kenya National AIDS Control Council (NACC): Nairobi.

11. National AIDS/STI Control Programme (NASCOP), 2012 *Kenya AIDS Indicator Survey: Final Report*. 2012, Ministry of Health, Government of Kenya: Nairobi.

12. National AIDS Control Council (NACC), National AIDS/STI Control Programme (NASCOP), *Kenya HIV Estimates 2014*. 2014, Ministry of Health, Government of Kenya: Nairobi.

13. National AIDS Control Council (NACC), *Kenya National AIDS Strategic Framework, 2014-2019.* 2014, Ministry of Health, Government of Kenya: Nairobi.

APPENDIX 1

FOCUS GROUP DISCUSSION GUIDE

1. What is the age range of the fishermen in this landing site? What is the youngest age that a male can be a fisherman?

2. Aside from fishermen, what are the other roles involved in getting the fish from the lake to market? What are their age ranges? Are they mainly men or women?

3. How do they interact with the fishermen?

4. How do they interact with each other? For example, how do fish traders or fish processors interact with boat owners?

5. What are other ways that women at the beach or surrounding area get fish or make money from the fishing industry?

6. When are the high seasons for fishing? The low seasons?

7. For how long (days, weeks, months) do the fishermen go out to fish? How long do they stay at the landing sites?
a) Do the other fishing community groups, like fish traders, follow the fishermen or do they usually stay at the same landing site?

8. When they go out to fish, do they often travel beyond Kenyan boundaries, to the Uganda and Tanzania parts of Lake Victoria? Do they land on beaches in Uganda and Tanzania? On the islands?

9. What is jaboya, or fish-for-sex?
a) Who is this transaction between?
b) How does it occur?

10. Who or what is abila?

11. How widespread is jaboya among this fishing community?

12. Are there other situations where money, goods, or services are exchanged for sex within the fishing community?

13. Do people have any concerns about this exchange, about their health or HIV?

14. Do people do anything to protect themselves from HIV when engaging in this practice?

15. In your opinion, how big a problem is HIV/AIDS among the fishing community?

a) How does it compare with other health problems in the community?

16. What do you think are factors that put people at risk for getting HIV/AIDS in the fishing community?

17. Are there particular groups of people who are at higher risk for HIV/AIDS than others?
a) If so, why are they are higher risk?
b)What, if anything, do people do to protect themselves from HIV?

18. How does HIV/AIDS affect this fishing community? The fishing sector overall?

19. Are HIV/AIDS-related services (e.g. HIV testing and counseling, treatment, male circumcision) available in this community? If so, what services are available?

20. Do you think many people in this community have accessed these services?

a. If yes, did people seem satisfied with the services provided? Why?

b. If not, what are the barriers for accessing these services?

21. Where do fishermen usually sell their fish? Is there a common place where they do this?

22. Where do fishermen usually go when there are on shore or to relax with other fishermen?

23. What are other places that the fishermen usually visit?

24. Where do the fish traders usually sell their fish? Is there a common place where they do this?

25. Where do fish traders usually go when they are not selling fish?

26. What are other places that fish traders usually visit?

27. What is a beach management unit?

28. How is it organized?

KEY INFORMANT INTERVIEW GUIDE

1. What is your current role and what work do you do with the fishing community?

2. What is the age range of the fishermen in this landing site? What is the youngest age that a male can be a fisherman?

3. Aside from fishermen, what are the other roles involved in getting the fish from the lake to market? What are their age ranges? Are they mainly men or women?

4. How do they interact with the fishermen?

5. How do they interact with each other? For example, how do fish traders or fish processors interact with boat owners?

6. What are other ways that women at the beach or surrounding area get fish or make money from the fishing industry?

7. When are the high seasons for fishing? The low seasons?

8. For how long (days, weeks, months) do the fishermen go out to fish? How long do they stay at the landing sites?
a) Do the other fishing community groups, like fish traders, follow the fishermen or do they usually stay at the same landing site?

9. What is jaboya, or fish-for-sex?

10. Who or what is abila?

11. How widespread is jaboya among this fishing community?

12. Are there other situations where money, goods, or services are exchanged for sex within the fishing community?

13. Do people have any concerns about this exchange, about their health or HIV?

14. Do people do anything to protect themselves from HIV when engaging in this practice?

15. In your opinion, how big a problem is HIV/AIDS among the fishing community?
a) How does it compare with other health problems in the community?

16. What do you think are factors that put people at risk for getting HIV/AIDS in the fishing community?

17. Are there particular groups of people who are at higher risk for HIV/AIDS than others?
a) If so, why are they are higher risk?
b) What, if anything, do people do to protect themselves from HIV?

18. How does HIV/AIDS affect this fishing community? The fishing sector overall?

19. Are HIV/AIDS-related services (e.g. HIV testing and counseling, treatment, male circumcision) available in this community? If so, what services are available?

20. Do you think many people in this community have accessed these services?
a) If yes, did people seem satisfied with the services provided? Why?
b) If not, what are the barriers for accessing these services?

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