

## ENHANCING HIV PREVENTION: SOCIAL SUPPORT, ACCESS TO, AND USE OF HIV TESTING, TREATMENT, AND CARE SERVICES IN FISHING COMMUNITIES AROUND LAKE VICTORIA, UGANDA

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In-depth interviews were conducted with 42 HIV-positive fisherfolk and 15 health care providers to identify experiences of social support and its influence on access to and use of HIV testing, treatment, and care. Fisherfolk participants reported receiving support at some point. Prior to HIV diagnosis, this usually took the form of advice on what illness they were dealing with and remedies to use. After HIV diagnosis and disclosure to friends or family, emotional support enabled fisherfolk to come to terms with an HIV diagnosis, informational support offered guidance on how best to live with HIV, while instrumental support enabled access to relevant HIV services. Finally, affiliative support, in the form of new friends met through HIV clinic visits, provided a sense of belonging. Each of these different kinds of support assisted fisherfolk to respond positively to HIV with important consequences for secondary and tertiary prevention.

*Keywords:* social support, HIV, fisherfolk, Uganda, secondary prevention, tertiary prevention

Fisherfolk—defined as all inhabitants living in communities where the main economic activities and livelihoods are derived directly and indirectly from fishing activities (Kiwanuka et al., 2014; Seeley & Allison, 2005)—are a key population in the Ugandan HIV response (Ministry of Health, 2018). HIV prevalence among them has been estimated at 22–29% (Asiki et al., 2011; Opio, Muyonga, & Mulumba, 2013) compared with the national average of 6% among adults aged 15–49 years

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(Ministry of Health, 2017). Current guidelines for the prevention and treatment of HIV in Uganda recognize fisherfolk as a high prevalence group (Ministry of Health, 2018) and stress the need for early detection and treatment to prevent onward HIV transmission, to reduce the immediate impact of the disease on individuals and communities, and to improve the long-term quality of life of people with HIV.

It is well established that HIV risk and vulnerability are influenced by a range of individual, interpersonal, and contextual factors (Aggleton, 2004; Gupta, Parkhurst, Ogden, Aggleton, & Mahal, 2008). Use of a socio-ecological model in research enables examination of how people's risk and health seeking practices are influenced by social, cultural, economic, and legal factors at intra-personal, interpersonal, institutional, community, and public policy levels of society (McLeroy, Bibeau, Steckler, & Glanz, 1988; Tumwine, Aggleton, & Bell, 2019). In Uganda, previous research has identified personal, interpersonal, community, and environmental factors associated with fishing livelihoods that account for fisherfolk's risk and vulnerability to HIV. These include poor access to health services, mobility which fosters an increase in HIV risk behaviors, a fatalistic attitude linked to the risks encountered in fishing, high levels of alcohol use, and transactional sex in fishing communities (Seeley et al., 2012; Sileo, Kintu, Chanes-Mora, & Kiene, 2016). In contrast, relatively little is known about fisherfolk's experiences with HIV testing, treatment, and care. Knowing more about these is key to both the secondary (early detection and treatment) and tertiary (improving quality of life and reducing symptoms of disease) prevention of HIV.

Networks and mechanisms of social support—sometimes provided in the context of relationships within interpersonal, institutional, and community settings—have been documented as an important influence on people's access to HIV care and treatment services in Uganda (Atuyambe et al., 2014; Nakamanya, Mayanja, Muhumuza, Bukonya, & Seeley, 2019; Rouhani et al., 2016; Tsai et al., 2012). Yet previous research has suggested fishing communities are different to other populations, as they tend to be poorer and have more mobile populations than non-fishing communities (Seeley & Allison, 2005; Sileo et al., 2016). Partly due to these features, social support to HIV-positive persons in such communities may be limited (Seeley & Allison, 2005). Social support for someone who suspects, believes, or knows they are living with HIV can take many forms, including material or instrumental support, emotional support, and informational support to enable the individual to access and/or remain in HIV care (Cohen & McKay, 1984; Rouhani et al., 2016). Material or instrumental support refers to tangible help provided by others, such as assistance with childcare or housekeeping, or the provision of money or transport (Rouhani et al., 2016). Emotional support involves things that other people do that enhance feelings of self-worth, as well as feeling cared for or loved (Cohen & McKay, 1984; Rouhani et al., 2016). Informational support includes the provision of information about health or functioning of local health care systems (Barker, Olukoya, & Aggleton, 2005). Yet research on these issues conducted in fishing communities is scarce. Specifically, it is unknown what forms of support are provided by family, friends, neighbors, colleagues, and professionals to HIV-positive fisherfolk and the impact that different forms of support have on access to and use of HIV testing, treatment, and care. In view of this, and as part of a larger exploratory qualitative study, we explored forms and influence of social support on access to and use of HIV testing, treatment, and care in these communities.

To address this gap in knowledge, this article examines how different forms of social support influence fisherfolk's access to and use of HIV testing, treatment and care. The specific research questions addressed are: what forms of social support are

available to HIV-positive fisherfolk; what role does this support play in facilitating fisherfolk's access to HIV testing, treatment, and care; and what factors mitigate fisherfolk's access to social support?

## METHODS

### STUDY DESIGN AND SAMPLE

Findings reported in this article are drawn from a larger exploratory qualitative study—involving semistructured in-depth interviews with 42 HIV-positive fisherfolk and 15 health care providers—which aimed to explore socio-ecological factors influencing fisherfolk's engagement in HIV testing, treatment, and care services in two communities around Lake Victoria in Uganda (Tumwine, 2019). The study was informed by the socio-ecological framework (McLeroy et al., 1988), which enables the identification of a number of levels of factors (and hence potential opportunities for intervention) relevant to secondary and tertiary prevention as defined above. To assess HIV-related social support, participants were asked to describe their health and help seeking experiences in the two years prior to HIV diagnosis and in the period that followed this.

### STUDY SETTING

To facilitate access to HIV-positive fisherfolk, the study was conducted in partnership with two selected clinics. The first of these, The AIDS Support Organisation (TASO) Entebbe HIV Clinic, is located in Entebbe Municipality on the shore of Lake Victoria. The other clinic, Kalangala Health Centre IV, is located on Bugala island in Lake Victoria. The two clinics were purposively chosen because they were known to serve large fisherfolk populations.

The TASO Entebbe Clinic is part of TASO Uganda, a nongovernmental organization started in 1987 to provide HIV-related services. TASO Entebbe provides HIV-related services in Entebbe Municipality and surrounding areas. The clinic is attended by various clients including HIV-positive persons from fishing communities. Additionally, the clinic runs community drug distribution points (CDDPs) at or near fish landing sites (fishing villages) around Lake Victoria that are largely attended by HIV-positive persons from adjacent fishing communities.

Kalangala Health Centre IV is a government funded public health facility in Kalangala district. It is located in Kalangala town on Bugala Island. Most of the people seeking health care services (including HIV-related services) from the facility come from Kalangala town, fishing villages/landing sites such as Kasekulo, Mwena, Lutuboka, Ddagi, Bbanga, and Kizira and the numerous islands surrounding Bugala Island.

### STUDY PARTICIPANTS

Two types of study participants were purposively recruited to this in-depth study: HIV-positive fisherfolk ( $n = 42$ ) and health care providers ( $n = 15$ ) involved in providing HIV care at the clinics through which the HIV-positive fisherfolk were recruited. In this study, a fisherperson was any HIV-positive person 18 years and above living (within a radius of 2 km) or working at a fish landing site/fishing community whose livelihood was directly or indirectly derived from fishing. They were recruited through the two clinics mentioned above. Health care providers recruited

to the study included counselors, nurses, and physicians directly involved in providing HIV testing, treatment, and care services at the two clinics.

### PARTICIPANT RECRUITMENT

Recruitment of HIV-positive fisherfolk took place by “trained expert clients” (Ministry of Health, 2018)—HIV-positive persons who have received training to support fellow HIV-positive persons (at the clinic and in community settings) in access to HIV services—who introduced the study to peers at each of the two clinics as they waited for their medical appointments. Clients who were interested in participating in the study and fulfilled eligibility requirements were referred to the first author to complete the consent process. Health care providers at each clinic were invited to participate in the study by means of an invitation letter. Those who were interested to participate were then invited to contact the first author to complete the consent process.

### DATA COLLECTION

In-depth semistructured interviews with fisherfolk and health service providers took place between October 2016 and February 2017. Interviews with fisherfolk aimed to elicit detailed narratives of participants’ experiences and perceptions of factors which facilitated or constrained their access to and use of HIV testing, treatment, and care in fishing communities. To triangulate this data and add further depth to analyses, interviews with health service workers were conducted to examine their experiences of providing HIV testing, treatment, and care services to fisherfolk. Particular attention was paid to examining how processes and procedures within health services enhanced or inhibited fisherfolk’s engagement with services in clinic and community settings.

Two topic guides specific to each participant group were developed to inform data collection. Interviews lasted between 42 and 148 minutes in length and were conducted in private rooms at the two HIV clinics or at venues in the communities where fisherfolk lived. All interview locations offered audio-privacy. Interviews with health service providers took place in English and interviews with fisherfolk participants were conducted in the participant’s first language (either Luganda or Runyankole). All interviews were audio-recorded.

Recordings were transcribed and translated into English by the first author and a research assistant, both of whom are fluent in Luganda and Runyankole. The first author checked the quality of the transcription and translation undertaken by the research assistant by listening to the interview recordings while reading the translated interviews and making edits to the transcripts where they were necessary.

### DATA ANALYSIS

Interview transcripts (with all identifiers removed) were uploaded into ATLAS.ti software to facilitate coding and were analyzed thematically using both deductive and inductive approaches (Bryman, 2016).

An initial stage of deductive coding sought to identify the everyday experiences of fisherfolk and perspectives of health care providers in relation to the major objectives of the study, which involved identifying socio-ecological factors influencing access to and use of HIV testing, treatment, and care in fishing communities. Analysis focused on the everyday experiences of fisherfolk and the perspectives of their health care providers. Each transcript was read twice to identify and code factors

perceived as influencing access to and use of HIV testing, treatment, and care at intra-personal, interpersonal, institutional, community, and public policy levels of society (McLeroy et al., 1988).

During the above process, the significance of different forms of social support became clear, especially at the interpersonal level. A second stage of deductive coding therefore took place informed by the following types of support: (1) emotional support, in the form of the expression of feelings that a person is well-regarded and valued; (2) instrumental or material support, including the provision of financial and material resources as well as assistance in completing a task; (3) informational support, in the form of help in defining, understanding and coping with problematic events; and (4) affiliative support or involvement with others in leisure or recreational activities.

Once data had been sorted into the emotional, instrumental, informational, or affiliative support codes identified by this framework, the data within each code was analyzed inductively to refocus analysis on participants' own narratives (Bryman, 2016). Inductive coding took place by a recursive process in which the first author (CT) read and re-read the data within each code, looking for local explanations and examples of the form each type of support took in influencing fisherfolks' engagement in HIV care services. In this way, we were able to identify the roles of different people in providing different forms of support, as well as occasions and instances where support was limited. The development of these inductive codes and the explanatory links between them was then reviewed by all co-authors.

### ETHICAL CONSIDERATIONS

Ethical approval for the study was received in Australia and Uganda. In Australia, the study was reviewed and approved by UNSW Sydney's Human Research and Ethics Committee (HC 16545). In Uganda, the study was reviewed and approved by the TASO Research and Ethics committee (TASOREC35/16-UG-REC-009). It was also reviewed and registered by the Uganda National Council for Science and Technology (SS 4145). Key ethical commitments adhered to throughout the study include voluntary participation, informed consent, confidentiality and anonymity. Participants were informed that they had the right to withdraw from participation at any time without explanation, but none opted to do so. Each participant signed a written consent form before the interview began. To protect confidentiality and anonymity, pseudonyms are used throughout this article.

## RESULTS

All study participants described experiences of fisherfolk receiving social support from friends, family, and others, and the impact of such support on access to HIV testing, treatment, and care. We first describe the forms and role of support received by fisherfolk participants and then the factors mitigating against fisherfolk's access to social support.

### FORMS AND ROLE OF SUPPORT RECEIVED BY FISHERFOLK PARTICIPANTS

Fisherfolk and health care providers' narratives of HIV testing, treatment, and care suggest that fisherfolk often received emotional, informational, instrumental, and affiliative support from family, friends, and neighbors as well as from professionals such as health workers, both before and after HIV diagnosis.

*Emotional Support: Feeling Right—The Importance of Friends and Family.* Emotional support is important to individuals because for a long time HIV and AIDS were associated with death and therefore those who suspected themselves to be or who had tested HIV positive perceived themselves as going to die soon. Fisherfolk and health care providers' narratives on access to health care suggested that emotional support was provided to HIV-positive fisherfolk both in informal settings by family, friends, and others and in more formal organizational settings by trained counselors and other health care providers.

Fisherfolk participants talked of being provided with emotional support in the form of encouraging words to engender hope for the future. Some participants described how HIV-positive family and friends shared with them their own experiences of living with HIV, and how these experiences enabled them to feel stronger and more hopeful. Other fisherfolk participants reported how work colleagues would visit them either at home or when admitted in hospital or would call them by phone to check on how they are doing. In addition, some fisherfolk talked of slowly overcoming their worries after meeting several other persons who were HIV-positive and who looked healthy and not worried, after entry into HIV care. All this provided reasons to be hopeful.

In the period immediately prior to HIV diagnosis, fisherfolk narratives suggest that health professionals who suggested HIV testing to them provided emotional support in form of pre-test counseling. When asked how she felt going for an HIV test, Annet (37 years, unemployed, lakeshore resident) said,

I was counselled first and when I was getting in to be tested for HIV, I had to become strong. My child had also been diagnosed with tuberculosis and HIV; so, when I thought about a young child having HIV when they had never been sexually active, I got strong.

Simon (39 years, fisherman/farmer, island resident) described his experience immediately after being diagnosed with HIV. He said, "When I remembered that I have young children to look after and realised I am going to die soon, I cried . . . My wife comforted me, telling me, 'Please do not cry.'" Norah (37 years, fishmonger and farmer, island resident) who reported going for HIV testing after suspecting that her husband could be HIV positive, described what happened immediately after she was diagnosed with HIV:

I fainted and I cried a lot when I was told I was HIV positive. I thought I was going to die and leave behind my children with no one to care for them. When I returned home a neighbour who was also HIV positive comforted me when she heard of my experience. She brought out her ARVs [antiretroviral drugs] and showed them to me and told me she was also HIV positive and that I should not worry about anything because I was going to be fine. She was very healthy and beautiful and when I saw her, I started to overcome my worries.

*Informational Support: "Knowing What to Do and Where to Go".* Fisherfolk participants who experienced illness in the period prior to HIV diagnosis described family members, friends, neighbors and relatives providing them with information and advice on what was likely to be affecting them, the remedies to use and which care providers to consult. Edmund (37 years, casual laborer, lakeshore resident), when asked how long he had been ill before being diagnosed with HIV, explained:



I had been ill for about 2 months; you know I was trying as much as possible to be seen to be strong. But after some time, many of my colleagues started noticing I was ill and they would comment, "What is happening to you?" So, when the comments continued to flow in about my health, I decided to go to the clinic. Actually, there is one colleague of mine who told me, "Bilharzia should be the problem afflicting you, and therefore you need to go to the hospital to get treatment." But when I got to the hospital and I was examined, I was not given drugs meant to treat bilharzia but some other drugs. After taking these drugs, I got better. It was after getting better that I was tested for HIV and told "You are HIV positive."

Similarly, Fred (35 years, construction worker, island resident) who had also experienced a long period of illness before learning he was HIV positive, described how his cousin (who he lived with) helped him in the period just before HIV diagnosis: "He used to give me advice telling me to go and test for malaria. By then, I was falling sick quite frequently, and at first he thought I had malaria. But when the illness frequency increased, he advised me to also test for HIV."

Following an HIV diagnosis, several fisherfolk participants reported disclosing to some of their friends and family members who in turn provided advice and information on how best to live with HIV. Christine (25 years, fishmonger and farmer, lakeshore resident) while talking about the kind of assistance her mother had provided her with after learning that she was HIV positive, said,

She even told me that my father died due to HIV way back in 1993 . . . They just told me that my father died because the drugs were not available then and that if you take HIV medicines you can live longer, and that you can have healthy children yet I had not had any child then, so I had to embrace taking HIV medications.

Annet (37 years, unemployed, lakeshore resident) when asked who else supported her (apart from her husband) after her HIV diagnosis, said, "My sisters told me, if you discontinue taking HIV drugs, you will die; so, try as much as possible to take your ARVs always. And even up to now, they continue to encourage me to take my drugs." Edmund (37 years, casual laborer, lakeshore resident) had been advised to seek health care by his friends after realizing he was gradually becoming weak. Following his diagnosis with HIV the same friends advised him to "be strong and . . . take the HIV drugs as directed by health care providers."

Informational support to fisherfolk participants came not only from informal social network members (such as family and friends) but also from professionals such as health care providers. Sarah (46 years, retail trader, island resident) when asked whether she has ever missed any clinic appointment, said, "I have never missed any clinic appointment. I have never missed taking any of my HIV drugs. The health workers educated me on what is necessary for me to remain healthy and I listened to their advice." Alex (39 years, fisherman and businessman, island resident) when asked whether he got help from anyone before starting to take ARVs, pointed out,

Before I was given ARVs, a counsellor at the health facility told me something that kept on my mind that, "If you take these HIV drugs, you will be helped, but if you don't, I won't mind about you. There are so many people out there who need these drugs but are unable to get them." This kept reminding me that I have to take my HIV medicines, since these will be helping me, and so many people would need these drugs but can't get the chance of getting them.

Interview data from health care providers backed up his claim. For example, when Rose, a health care provider at the lakeshore clinic, was asked how she engaged with clients who come requesting more drugs when they plan to travel away from home, she replied,

That usually happens, but the way I handle them depends on a number of things; if a person is scheduled for viral load follow up or that person is pregnant or has an infection that you need to monitor in a short period, you explain the benefits of postponing their travel plans and coming back to the clinic sooner . . . . We generally have a discussion with clients having difficulties to come back to the clinic for treatment on how best to go over those difficulties and return to the clinic for care. As a health worker you cannot allow someone who is pregnant or who has a high viral load to stay away from the clinic for over 3 months because they might come back in a worse situation after that long period.

*Instrumental Support: "Getting by With a Little Help From Others".* All the fisherfolk participants reported receiving instrumental support at some point in their health seeking experience. This support was seen as valuable by participants because it enabled them to access the HIV treatment and care they needed.

Fisherfolk and health workers' narratives on access to HIV testing, treatment, and care provided numerous examples of occasions when fisherfolk were provided with instrumental support in the form of food and drink, money and accommodation. This support was especially forthcoming during periods when fisherfolk participants were sick and unable to work.

Zainabu (40 years, bar owner and fishmonger, island resident) reported receiving material support from friends/neighbors in the period before HIV diagnosis:

So, when I got very ill while living on the island, my neighbours and other colleagues who were living on the same island contributed money that was used to transport me back home. So, the local leaders on our island went around with their book soliciting for and recording contributions from residents to assist in relocating me to my mother's home in Luwero district.

Esau (60 years, farmer, island resident) talked about the material support his family had provided after diagnosis, ". . . my young brother who I had told you about is the one who supported me with some money. Even up to now, whenever I have got a problem he helps me because he is aware of my situation." When asked whether his brother helped him because they were related or because he was HIV positive, he said, "He supports me because he is aware that I am HIV positive. So, when he gets to know that I have a problem, he sends me some money."

Judith (43 years, farmer, island resident) described how she had moved to live with her mother (in a non-fishing community) when she became ill, and it was during this time that her mother first advised her to test for HIV. When asked what kind of support her mother provided, she said,

She would look after me very well. If I would tell her that the health worker has recommended that I eat nutritious food, she would buy everything that would have been recommended and make it available to me. Later, she would call me on phone to ask how I was doing. And she would tell me, "If you feel sick, please come home and I will take care of you." I stayed at my mother's home for 9 months and for all that period she was taking good care of me. And by the time I returned to my home, I had healed and very okay.



Other forms of instrumental support included physical help when fisherfolk were unable to walk to hospital, providing them with medicines—both traditional and modern—and taking on some of the work that would otherwise need to be performed by participants. Sylvia (47 years, farmer, island resident) described her experience:

I disclosed my HIV status to my sisters after the death of my husband. They had realised that he had died due to an HIV-related illness and they knew he was HIV positive. . . . Even before I disclosed to them my HIV status, some would exempt me from doing hard work for instance during family parties; this they would do because they knew I was HIV positive. So, when I would work very hard during such occasions, some would tell me, please take a rest because you are straining yourself too much.

Zainabu (40 years, bar owner and fishmonger, island resident) reported temporarily moving back to her mother's home in a non-fishing community when she became ill, and described the help her mother provided:

So, when the health workers started treating me, I was still not interested in receiving this kind of care. So, the medicines they would give me to take, I would just throw these away, not knowing that I am approaching the point of dying. So, when my mother checked my bed, she found nearly all the medicines I was supposed to have taken under the bed, and she decided to supervise my taking of the medicines closely. So, she would sit in front of me to ensure that I swallow the drugs until I completed the entire TB [tuberculosis] dose. And after I completed the entire dose, I got healed and became okay. Before then, I was never interested in swallowing drugs. And ever since that period, I have never thrown away any other medications given to me here at the HIV clinic.

Judith (43 years, farmer, island resident) said,

My husband is also HIV positive and so he ensures that we have good nutritious food to eat such that we can be able to continue to take our ARVs well. And we take our HIV drugs at the same time, so, sometimes he helps to remind me that it is time for us to take our HIV drugs.

Fisherfolk participants' partners, sons, and daughters and other family members sometimes acted as liaison points with the treatment centers. Esau (60 years, farmer, island resident), for example, when asked about the help he received from his younger brother said, ". . . during those days I had no phone, so, whenever I would be needed here at the clinic they could call him and he [then] passes on the information to me." John (42 years, fisherman, lakeshore resident) when answering a question about whether his travel away from home affected his access to HIV care, said,

Even my sister is aware that I am HIV positive. I had put her telephone number on my clinic file and it is that number that health workers would use to contact me. When health workers call her on phone, she would also call me on my phone to inform me about the information she would have received from the health workers.

Emily (32 years, fishmonger, lakeshore resident) described a slightly different relationship with the local treatment center, facilitated by a friend who picked up medications on her behalf:

I have sent in a colleague once to pick medicines for me. She was also HIV positive and getting her HIV drugs on the same clinic date as me and living close to where I live. So, on that day, I had gotten a lot of fish (silver cyprinid/mukene fish) to prepare for sale and I could not be able to come to the clinic to pick my drugs. So, I approached the colleague and asked her to help me and pick my drugs from the clinic and bring them to me. She hesitated a bit at first while saying, “I am not sure whether the health workers will give me your drugs to bring them to you.” But I told her, just tell them I am ill, and they will be able to give you the drugs. Afterwards, I gave her my medical card to come with it to the clinic and she was able to bring back the drugs for me.

Judith (43 years, farmer and fishmonger, island resident) had lost her eyesight for a period of time just before the interview and had explored strategies to lessen the burden of seeking HIV care when blind. So, she opted to change clinics, from one on the lakeshore to another located on the island on which she lived. In the process of talking about how long she had been taking her medication intermittently—because of her fear that her vision problems were related to the ARVs—she said,

I was getting my HIV drugs from a clinic on the mainland; . . . but when I got sight problems I decided to come to this clinic [on Bugala island] which is near where I live, to get my HIV drugs from here. So, I sent a message through my neighbour/friend to a health worker here to find a way of helping me to get HIV drugs. . . . [After] I sent the neighbour to deliver my message to the health worker, I was immediately picked up and brought to this clinic. My neighbour physically supported me on the journey to this clinic and she also asked to [have a] test for HIV when she got here [at the HIV clinic]. She also tested HIV positive and started to take HIV drugs soon after.

Several health care providers described sometimes working with their clients’ friends to ensure that HIV-positive fisherfolk were able to receive HIV treatment without interruption. Elizabeth, a health care provider explained what might happen when a client needed to travel away for a period of time:

Clients who are already in our care and are taking their HIV drugs well sometimes come in 3 or 2 days earlier to their appointment requesting for drugs. They can come in early saying, “I am travelling, and I am going to stay away for 4 or 6 months, please help me and supply me with enough drugs to take me for such a period of time” . . . . So, we support them and provide them HIV drugs that can take them for about 3 months. And when such clients have travelled to a far-off place and they have a buddy who can help them and pick their HIV drugs from here and send such drugs to them, we can give them the HIV drugs to forward to the client.

*Affiliative Support: “Belonging in the Context of HIV”.* Fisherfolk narratives of the support received prior to and after diagnosis yielded illustrations of when affiliative support/companionship and access to HIV-related services might be linked together. In one such instance, Simon (39 years, fisherman and farmer, island resident), while talking about how HIV-positive people in his community supported one another, provided the following illustration of how companionship could facilitate the process:

But for me, I am always at the forefront of bringing together HIV-positive people in my community such that they can be able to take on different activities. For instance, when

we were on the boat coming to the HIV clinic today, we resolved to start a savings group such that we can collect our own money that can help us. When one is HIV positive and doing well economically, they don't feel the pain of being HIV positive. When we start our own savings group as HIV-positive people living on our island, we can be able to assist colleagues using our savings.

Other fisherfolk described having become friends with other HIV-positive people they had met at the treatment centers, largely because such persons were able to understand the participant's circumstances. Fred (35 years, fisherman and construction worker, island resident), for example, said,

It was only after I enrolled into HIV care that I got a number of friends who were also in HIV care that have been helpful to me. For instance, that man who has just passed, became my friend after I met him at the HIV clinic. When I was unable to work, he has been helpful to me. So, now I collaborate more closely with people who are HIV positive, who are able to help me when I am in problems.

#### FACTORS MITIGATING AGAINST ACCESS TO SOCIAL SUPPORT

Although every participant in the study described receiving support at some point which facilitated access to and use of HIV testing, treatment and care, some also described occasions when they received little social support. As a result, they were unable to keep clinic appointments or take their medications as prescribed. Several of these participants specifically described not having access to funds for transport and lacking the material support necessary to enable them to be more actively involved in HIV care.

Health care providers' and fisherfolk's accounts signaled a number of reasons why social support might not be readily available. In particular, they highlighted the importance of disclosure as an important factor influencing whether or not the HIV-positive person would receive support from within their social network. Non-disclosure of HIV status by some fisherfolk participants to friends or family members was viewed as a major reason why they had not sought or received help from friends and family. Reasons for non-disclosure included the fear of stigmatization or the belief that it was not necessary to disclose to others.

Sometimes non-disclosure occurred because relevant individuals were not living with or close to the fisherperson. Annet (37 years, unemployed, lakeshore resident), for example, when asked how her children had supported her in accessing HIV care, said,

The older children are now living with my ex-husband and they are not aware that I am HIV positive. I am not constantly in touch with these children, and the younger children that I live with are still very young to understand what HIV is about.

Sylvia (47 years, farmer, island resident) said,

When I returned from HIV testing, I never disclosed to anyone apart from my friend. For the people that were close to me such as my mother and sisters, I never told them that I had tested HIV positive because I thought they would get very sad, and so due to this they could not help me.

When asked what could be done at the family level to help fisherfolk who are HIV positive, Ben a health care provider from the island-based clinic drew attention to these and other factors when he said, "Some HIV-positive fisherfolk do not have long-term partners or do not want their partners to know that they are HIV positive and in HIV care, and due to these reasons it may also be difficult to involve their families to help them."

In some cases, participants reported not seeking support from their own children because they were still too young, or from others such as grandparents because they were too old (or poor) to be able to offer material support. Several participants described how they were the ones expected to provide support to others, not the other way around. Generally, study participants believed that young children cannot directly provide emotional support to an HIV-positive person because they do not understand what HIV is all about. Simon (39 years, fisherman and farmer, island resident), when asked what support his children (oldest was reported to be 14 years and youngest 6 years) gave him in relation to his treatment experience, said,

The only help they can give me is to remind me to take my HIV drugs. They also remind their mother when it is time for her to take HIV drugs. Apart from that, there is nothing else that they can provide me because they are still young and do not have anything.

The elderly were seen by some study participants as being able to provide emotional and informational support but not material support because oftentimes they were economically dependent on others. As Annet (37 years, unemployed, lakeshore resident) put it, "There is no way that my grandmother could be able to help me because she was very old, and it is actually me who was supposed to be helping and supporting her."

The physical health of the HIV-positive person was seen as playing a role in whether participants had sought support in the past. Several participants reported that they did not need to seek material support from anyone because they were still physically strong and able to work and support themselves or travel to clinics with no need to be physically supported. When Umar (61 years, farmer and businessman, island resident) was asked whether his neighbors had supported him in any way after they learned that he was HIV positive, he said, "The neighbours did not support me after learning about my HIV status because, although I got ill, I have never been bed-ridden. So, I could be able to travel by myself to go to the hospital."

Findings also suggested that when a participant perceived themselves to be better off than or on equal standing with a family member or friend, then they did not expect them to provide to them any material support. Eunice (31 years, farmer, island resident) reported having disclosed her HIV status to her siblings after they asked her why she was taking some pills. When asked whether her siblings supported her after learning she was HIV positive, she said, "They have not supported me because for many of them, they are not doing well economically too." Similarly, Grace (30 years, bar owner and fishmonger, island resident), when asked whether her sister supported her, said,

She does not have any kind of support to give me, because she does not have money. . . . I even left her behind without any help when she was complaining of pain in one of her breasts. But I could not help her because I had only 100,000 shillings to enable only me come here.

Health Centre policies regarding when and how often a friend or family member could collect medications on behalf of someone else also affected the support available. Health workers reported needing to monitor the HIV-positive individual to ensure the treatment they were receiving was working. Edmund (37 years, casual laborer, lakeshore resident) explained:

In the past the health workers preferred to have the HIV-positive person pick the drugs themselves rather than sending in representatives. The reasoning for this was that health workers needed to regularly examine the HIV-positive person and if they now send in a representative, they are unable to monitor the HIV-positive individual and this does not make sense to them.

Sometimes health workers needed to provide the individual with information, which if passed on through representatives might not be delivered or messages might become distorted in some way. Even when family members and friends helped an HIV-positive person by picking up their medications for them, health workers generally required that the client attend the clinic personally at least once every 6 months in order to be assessed. Elizabeth, a health worker from the clinic on the lakeshore said,

When such clients have travelled to a far-off place and they have a buddy who can help them and pick their HIV drugs from here and send such drugs to them, we can give them the HIV drugs to forward to the client. But after a certain period, we insist that the client has to come to the clinic to pick the HIV drugs themselves and to do the viral load test.

## DISCUSSION

In this study, fisherfolk participants reported receiving support from friends, family, and health workers at some point in their health seeking journey, which facilitated their access to and use of HIV treatment and care.

Prior to diagnosis, fisherfolk participants were provided with emotional support which enabled them to cope with the otherwise frightening experience of suspecting or learning that they have HIV. Informational support at this same time helped encourage participants more accurately identify the illness they were suffering from and seek treatment. While the information provided was often appropriate and included referral to HIV testing, treatment and care, sometimes it was less so, with participants being encouraged to seek care from traditional healers when a modern health care provider would have been a better option. Emotional support from health care providers, friends and family members was especially important in the period immediately following HIV diagnosis. Findings from this study are consistent with those from other research including a recent study of young people newly diagnosed with HIV in Kibera, Kenya where the provision of emotional support enabled them to cope with stigma and gain greater self-acceptance (Lockwood et al., 2019).

Instrumental support in the form of food, money, accommodation, and other necessities was extended to fisherfolk both before and after HIV diagnosis. Material assistance in the form of money for transport costs enabled fisherfolk to access testing and treatment centers. Instrumental support was also provided in periods when participants were ill and unable to work. Friends and family also helped clients pick

up medications from HIV treatment facilities, findings which are consistent with those reported by others (Rouhani et al., 2016; Sileo, Reed et al., 2019).

Affiliative support was provided to fisherfolk during clinic visits when participants interacted with others seeking treatment and care. Participants described identifying with other HIV-positive persons they met at the clinic and feeling a sense of companionship from HIV-positive peers who lived locally. This study, to our knowledge is the first to describe this kind of support to HIV-positive persons in the settings in which this study was conducted. Factors mitigating against access to social support included HIV status non-disclosure, perceiving available friends and family as being either too old or young to help, and seeing oneself as physically well and therefore not needing support. Health center policies regarding when and how often help could be extended to clients with respect to the collection of HIV drugs both facilitated and affected the support available. This study we believe is one of the first to describe these factors in the Ugandan context.

Taken together, findings in this article complement the small but expanding literature documenting fisherfolk's experiences of accessing HIV treatment and care in Uganda. Recent research has described the influence of ideologies of masculinity (Sileo, Reed et al., 2019), patterns of alcohol use (Sileo, Kizito et al., 2019) and general access to health care (Bogart et al., 2016; Sileo, Wanyenze, et al. 2019), as influences on HIV-related health care seeking practices in these settings. This article adds to this work by providing an in-depth account of how different forms (emotional, informational, instrumental, and affiliative) of social support also facilitate access to HIV testing, treatment, and care.

### LIMITATIONS

Like all studies, this one is not without its limitations. It involved a convenience sample of fisherfolk and health care providers drawn from two clinics located in two fishing communities in Entebbe and Kalangala. Due to the small sample size and the convenience nature of sample selection, study findings may not be generalizable beyond the particular study setting. In addition, the study sample was drawn only from within fishing communities. Future research might usefully include participants from non-fishing communities to focus in on the specificities and uniqueness of fisherfolk experience against the backcloth of the social support available to other people living locally.

### IMPLICATIONS FOR POLICY AND PRACTICE

The findings documented in this article have important implications for HIV testing, treatment, and care in Uganda and beyond. As health care providers and others work towards achieving the UNAIDS 90-90-90 strategy by 2020 (Joint United Nations Programme on HIV/AIDS, 2015)—where it is aimed to have 90% of all people living with HIV know their HIV status, 90% of all people diagnosed with HIV receive sustained anti-retroviral therapy (ART) and 90% of all people receiving ART achieve viral suppression—there is need for HIV programs to work closely with all those who can help community members engage with HIV testing, treatment, and care. With growing concern about inadequate progress to meet these targets and about the clinical focus that such biomedical targets encourage, there is renewed emphasis on the importance of community-led responses to HIV prevention (Bekker et al., 2018). Friends and family are among the community-based actors who can provide ongoing support to persons who might benefit from HIV testing and those



already in HIV treatment and care to actively engage with services, thereby securing better outcomes.

Findings also suggest that the social support provided by family and friends to HIV-positive fisherfolk is important in facilitating what is likely to be lifelong access to HIV treatment and care. Current guidelines for prevention and treatment of HIV in Uganda (Ministry of Health, 2018) note the value of working with existing community organizations and organizational structures to help provide long-term psychosocial support to populations such as fisherfolk who access HIV care in clinics less regularly. Our study illustrates the benefits of having dedicated trained counselors, social workers, and trained expert clients linked with HIV testing, treatment and care facilities but located in community settings, who by their training and personal HIV experiences are more inclined to recognize and harness the support of friends and family to HIV-positive persons.

## CONCLUSION

All fisherfolk participants in the study reported receiving some form of support from friends, family, and health workers at some point which facilitated their access to HIV testing and involvement in HIV treatment and care—thereby contributing to important secondary and tertiary prevention goals. However, several participants also reported occasions when the support available to them was inadequate and this explained at least in part their periods of less active involvement in HIV treatment and care. Factors mitigating against access to social support included HIV status non-disclosure, perceiving available social network members as being either too old or young to help, and seeing oneself as physically robust and therefore not in need of material support. The socio-ecological framework adopted by this study helps makes better sense of these seemingly contradictory responses in a community severely affected by HIV, signalling the need for future programs to encourage the involvement of a wide range of “others” (friends, family, co-workers, and health professionals) in the local HIV response.

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