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Qualitative analysis of the intersection of HIV and socioeconomic factors impacting community health on Mfangano Island, Lake Victoria Region, Kenya

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Professor Lia C. H. Fernald

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Dedicated to my host family - Nicholas Olambo and Lilian Olambo and their children Oyuga, Oganda, Aman, and Atis - for opening their hearts and home to me.

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Paper One: Literature Review

I. Background

Introduction: The Triple Crisis
I traveled to Kenya to work during the Summer of 2011, a year that was described as the "great food crisis." The U.N. Food and Agricultural Organization announced that its food price index peaked at an all-time high at the close of 2010, ushering uncertainty in economic markets and volatility in social stability at the eve of the new year and for future years to come.

Just the year before in 2010, the U.N. University World Institute for Development Economics had convened to address the "triple crisis of finance, food, and climate change and its implications for poverty, inequality, and human development." The global financial crisis which began in 2008 in the financial systems of the North had sent reverberations across the world, "no country, rich or poor, is unaffected by contagion across financial markets." At the same time, climate change remained unabated, becoming an increasing driver of poverty. The poor are the main victims of environmental stress, and also have the least amount in resources and power to mitigate climate related consequences. Against this backdrop, increasing demand for food had strained current food supplies and production. Food riots had sparked across the developing world, in which the poor, already hardest hit by malnutrition and hunger, were forced into further vulnerability. Sustained high prices amidst a global financial crisis have pushed millions into poverty with estimates as high as over 100 million - losing years in gains in poverty reduction. The convergence of the triple crisis continues to disproportionately affect the world's most vulnerable, and how these global factors intersected in Kenya further compounded the vulnerability of the rural poor surviving at the edge of interlocking socioeconomic factors - communities so impoverished, so food insecure, and so dependent on their natural environment survive.

For the time I was in Kenya, I did not have much access to the outside world since I lived among remote, rural island communities within a vast in-land lake in which Kenya borders. And yet, salient social, economic, and political events interwove to frame the broader context that conditioned my experience. I pieced together the events surrounding and affecting Kenya through a haphazard array of resources. From newspapers that had traveled in from the Kenyan mainland, passed down by boat passengers, to our island communities. From the radio that sounded news from Nairobi over dinner, followed by conversations to interpret them from Kiswahili into English. Even from concerned phone calls from friends and family relaying news being broadcast in the news abroad.

During my stay, I learned that Kenyan food prices had rose sharply over the course of the year for basic commodities such as maize, a main food source for most Kenyans. The Kenyan Ministry of Agriculture announced that the remaining reserves of maize could only last two more months, with speculative hopes that the early August harvest may help replenish the low supplies. The government had quote “thrown open” the importation of duty-free maize to ease the serious shortage. Stories of families dying of
hunger were constant reminders of how vulnerable those closest to poverty were. Refugees entering Kenya from its neighboring country Somalia had further exacerbated the famine in Kenya’s north. These families had escaped both famine and war, although the severe drought in the north did not offer much reprieve. News of governmental corruption were as egregious as they were common – the Ministry of Special Projects acknowledged millions in international food aid were lost in a string of corruption scandals, the Ministry of Education could not account for millions allocated for primary education, and Members of Parliament collectively refused to pay income taxes articulated by the new Kenyan constitution.

It was living among one of Kenya’s most rural, remote communities, embedded in their narratives and experiences, that I began to understand the salience and complexity of the socioeconomic context in which they confronted and its impact on their lives. Although the communities that welcomed me into their lives were not living amidst the regions most severely impacted by these critical events, the convergence of such significant socioeconomic factors had effects that reverberated throughout Kenya and inevitably framed community perceptions of the broader context in which they lived in.

**How the triple crisis converged in Kenya**

Kenya is located in Eastern Africa, bordering the Indian Ocean to its east, as well as, sharing national borders with Ethiopia, Somalia, South Sudan, Tanzania, and Uganda. The geography of Kenya is complex, with its various microclimates and landscapes. The Kenyan northern and eastern landscapes are arid and semi-arid. These regions have been affected most by consecutive seasons of poor rainfall. Most acutely, below average rainfall (a fall of over 50%) in 2011 had exacerbated food insecurity in Kenya and in most parts of the larger Horn of Africa, a region encompassing Kenya as well as Somalia, Ethiopia, Eritrea, and Djibouti. The region is known as one of the most food insecure areas in the world, characterized by frequent droughts and conflict. Furthermore, rising food prices in the region had worsened the food security crisis.

Agriculture is the main economic sector for Kenya, 75-80% of the population is rural. The proportion of the population living with less than $1 a day is nearly 1 in 4 (23%); over half the population lives below the national poverty line (52%). Released in March 2011, the Government of Kenya’s Food Security Steering Group report documented a rapid decline in food security among agricultural households affected by the drought. The number of people needing food and other assistance rose by 50% in just six months, from 1.6 million in August 2010 to 2.4 million in February 2011. Furthermore, the worsening conditions in neighboring countries had hastened the spread and deepened the severity of food insecurity.

On May 30 2011, Kenyan President Mwai Kibaki declared a national drought emergency, mandating urgent distribution of food and relief supplies to northern and eastern Kenya. Between 3 - 3.5 million people were affected by the drought, and approximately 2.4 million were food insecure. Furthermore, drought, famine, and conflict-affected refugees from neighboring Ethiopia, Somalia, and Sudan continued to arrive and to settle in northern Kenya, with refugee numbers approaching half a million.
Socioeconomic context of Mfangano Island
For my summer, I lived in the western region of Kenya on Mfangano Island, an island that lies in the eastern part of Lake Victoria. Mfangano is one of the subdivisions of the Suba District of Nyanza Province, Kenya’s lake province (Nyanza meaning ‘lake’ in the Suba language). Lake Victoria is Africa’s largest lake by area, and the world’s largest tropical lake and second largest fresh water lake by surface area. Lake Victoria is so far-reaching that I could not see the end of it on the horizon. I would soon learn its importance to the communities that lived along its shores.

Mfangano Island is approximately 65 km² and rises to 1,694 meters, and is home to approximately 20,000 people, whom are mostly of Luo and Suba descent. According to their oral history, their communities represent the geographic convergence of clans from present day Uganda and present day Sudan over thirteen generations ago.

Subsistence farming and fishing are primary occupations for the majority of community members. As a summer visitor, I was present during the season of the harvests and thus sheltered from the most precipitous effects of the surrounding drought and famine occurring in Kenya and throughout East Africa. At the time August was soon approaching, and one could begin to see maize being dried almost everywhere, ready to be grounded into flour, and to be preserved for the months ahead. Based on a 2010 health and demographic survey, 87% of surveyed households from three Mfangano villages owned farmland. Many are subsistence farmers described as a “hand to mouth” existence. Subsistence farming is a livelihood strategy in which the main agricultural outputs are consumed directly. It is characterized by smallholder agriculture, in which farming provides the principle source of food and income and depends on mainly on family labor. As shared by my host father, maize and other crops are grown to last through one year, until the next harvest can secure food supply. Subsistence families, like my own host family, rely solely on the labor of their household members to survive. Their land and their labor is the only assurance against the increasing pressures of poverty, food insecurity, and ecological change. Complex interaction of multiple, interlocking socioeconomic stressors would have significant impact on the lives of subsistence communities due to their heightened vulnerability and limited ability to respond to changes.

Furthermore, Mfangano communities are largely dependent on Lake Victoria for food and income. Now, this does not mean the Lake Victoria region is food secure - having all-time access to sufficient, safe, nutritious food to maintain its communities. Studies by the Kenya Marine and Fisheries Research Institute has well documented that the communities of Lake Victoria are among the most impoverished and malnourished in Kenya. Furthermore, volatile global prices for basic necessities, such as fuel and flour, as well as ecological changes to the environment, such as unpredictable rainfall, have made community lives based on basic subsistence even more precarious. During my stay, many community members had shared that they do not have enough food throughout the year. Despite being such a vast natural resource, Lake Victoria had experienced drastic, deleterious transformations that would permanently reshape the lives of its indigenous communities that are most dependent on it to survive.
Transformation of Lake Victoria

Historical and current global socioeconomic forces have irreversibly altered the ecology and economy of Lake Victoria. Lake Victoria’s Nile perch fishing industry has had the most profound impact on its surrounding communities, as well as Kenya as a whole. Before colonial rule, Lake Victoria was an artisanal fishery that existed in harmony with the communities that used its resources. Traditional and territorial rules and regulations ensured that the shared commons was used in a sustainable manner.

The history of colonization and neocolonization drastically transformed the Lake Victoria region. Most significantly, in 1954, the invasive species of Nile Perch (*lates niloticus*) was introduced into Lake Victoria by the British Colonial Administration to "develop" the lake into a profitable export fishery. By 1980, the "Nile perch boom" had begun, and permanently altered the region’s ecosystem and the lives of its indigenous people. The most adverse ecological effects have been the irreversible transformation of the ecosystem and the threats to the sustainability of these crucial fisheries. Lake Victoria experienced the most rapid mass vertebrate extinction in recorded history with over 300 native fish species becoming extinct.

Lake Victoria dominates Kenya’s fishing industry, in 1995, 94% of the fish produced were from Lake Victoria. The lake borders and water is shared with Uganda and Tanzania, with Kenya only claiming 6% of Lake Victoria’s total surface area. Yet, Kenya’s side is the most heavily fished, commercialized, and productive of the three countries, yielding an estimated 33% of the total fish output (as documented in 1990). Lake Victoria is estimated of exhibiting an annual catch of approximately 500,000 metric tons, producing an annual income of $600 million USD.

Livelihoods around Lake Victoria rely mainly on fishing, since limited alternative economic opportunities exist. A fishery is a unit engaged in fishing activities, such as raising and harvesting fish. It is defined in terms of people involved, species of fish, area of natural resource, methods of fishing, and fishing related sectors. Due to compounding economic, environmental, and social factors, the shared fishery started to decline over the years, which included diminishing fish stock, declining average income of fishermen, employment displacement and transfer of benefits to commercial sectors, and less fish for domestic consumption. The supplies of fish started to diminish following escalation of fishing pressure due to overexploitation, environmental degradation, and invasive takeover by non-native fish species. Fish production peaked in the early 1990s, however currently most fish species have faced downward trends in which breeding cycles could not replenish the speed in which they were being depleted. This led to more drastic and irresponsible fishing practices that further diminished the fish stock, such as catching smaller fish that had not reached sexual maturity. Furthermore, as the main lifeline for the communities surrounding it, Lake Victoria continues to lose water. Water levels have dropped over six feet within four years between 2005 - 2009, which has destroyed important breeding grounds for fish on the edges of the lake. The water quality of Lake Victoria has also deteriorated over the past few decades due to environmental perturbations, which has significant impact on its complex biodiversity.

The declining fishery has had serious implications for the web of livelihoods and industries dependent on it. Fishery sectors have an estimated ratio of 1:3 in direct
fishing to downstream activities, such as trading, processing, and those involved in ancillary industries, such as hotels for traveling fishermen. Over the past decade, Lake Victoria provided employment benefits for nearly half a million people since the late 1990’s to now over 3 million people, and supports a growing population of over 30 million people who live on along its shores. Thus, macroeconomic changes to Lake Victoria have had ‘domino-like’ effects on the local economies dependent on it.

The export-oriented fishing industry, which prioritized an asymmetrical economic exchange, has intensified the inequities and vulnerabilities faced by communities of the lake region. Lake Victoria has been documented to yield up to 85% of Kenya’s total fish supply, and yet its communities have been characterized as being very food insecure, especially in protein intake. The highest levels of malnutrition in Kenya have been found within fishing communities, because they consume very little of what they harvest and have no access to supplementary sources of protein. Most of the mature Nile perch caught goes to factories for processing and export (Niru). Furthermore, Kenya’s lake province, Nyanza, remains one of the most impoverished regions of Kenya, a reality that is reflected in other lakeside regions of neighboring countries. Although income from the fishery has increased over the years, its distribution had become increasingly more inequitable given the structure of the export-oriented fishing industry. Over the years, local communities have been progressively driven out of activities they traditionally participated in, with commercial fish factories and their agents tightly controlling production chains from beginning to end. Previously women were a large part of the traditional fish trading and processing sectors, however, these services are now integrated in larger commercial marketing chains. This has resulted in an inequitable distribution of income positioning local communities at greater disadvantage - both in accessing fish and in their ability to generate income.

The catastrophic storm: HIV
For communities of Lake Victoria, the socioeconomic and ecological consequences of the globalized fishing industry led to deleterious impacts on community health. In 2006, the U.N. Food and Agricultural Organization released a policy report that summarized the impact of HIV/AIDS on fishing communities throughout the world. Based on research in the last decade, it became evident that in many fishing communities throughout the developing world, fishermen suffer from HIV prevalence rates often five to ten times higher than the national average rates of the general population. Often, these rates have been higher than other at risk sub-populations such as truck drivers, military personnel, prisoners, injection drug users, and sex workers. This heightened risk and vulnerability among fishing communities stem from the structure and dynamic of the fish trade and lifestyle in which several risk factors converge. Furthermore, the same circumstances that may put someone at risk for HIV infection also affect their access to treatment, care, and support, such as social marginalization, lack of institutional support, and income and power disparities.

The economy of the Lake Victoria region is characterized by an exploitative, globalized fishing industry, which has been linked to extensive population migration, practices such as transactional exchanges of “fish-for-sex”, pervasive food insecurity and malnutrition, entrenched impoverishment and underdevelopment, and natural resource degradation. Fishermen have been documented to be up to five times
more likely to die of AIDS-related illness than farmers in certain communities in the Lake Victoria region. Seroprevalence rates in lakeshore towns and villages in Kenya, Tanzania and Uganda have reached as high as 30-70% during the late 1990s, and continue to experience one of the most critical concentrations of HIV in the world.

Nyzana Province, in which Mfangano Island resides, has the highest HIV prevalence in Kenya, with more than twice the national HIV prevalence.

Complex and intersecting factors heighten risk and vulnerability to HIV/AIDS among fishing communities. These factors include the high mobility of fishermen, extensive time spent away from families and communities, sexually active demographic profile of fisherman, disproportionately high cash income in the context of widespread impoverishment, commercial and transactional sex exchanges, and sub-cultures of risk-taking and hyper-masculine behavior, including alcohol and drug abuse. Young, highly migratory fishermen spend long periods away from their families and local communities. Consequently, the social structures and hierarchies that guide sexual norms are not maintained. Among fishing networks, social ties are based mainly on economic relationships and interactions among occupational peer groups. These networks enable cultures of unrestricted sexual and behavioral norms and practices.

Furthermore, the gendered dynamics of fishing communities in the socioeconomic context of widespread poverty potentiate several key contextual factors that shape HIV/AIDS risk such as gender inequity and highly differentiated occupational sex segregation. A 2004 U.N. Population Fund report highlighted that in sub-Saharan Africa, “57% of adults with HIV are women, and young women aged 15 to 24 are more than three times as likely to be infected as young men.” HIV prevalence rates are expected to be even higher among women of fishing communities. Gender inequities that contribute most to their vulnerability to HIV/AIDS including initiation of sexual activities at an earlier age than men, lack of negotiating power on safer sex practices, lack of control over decision making, low level of education, and poorly enforced legislation related to women’s rights.

Furthermore, more extreme socioeconomic inequities may further exacerbate underlying gender inequities. In fishing communities, women usually do not engage in fishing themselves, instead they engage in secondary tasks, such as selling, trading, or processing - all which depend on male fishermen to supply fish. Women often occupy subordinate social and economic positions, which heightened their risk for HIV infection. Over the years, "fish for sex" transactions have been well-documented, and often characterized by sexual relationships with male fishers to secure supply of fish. A 2008 global review of literature revealed that “fish-for-sex” is not an anecdotal practice, but one that is increasingly reported among fisheries in developing countries. Data from the review highlighted that over 90% of such transactions have been observed to occur in inland fisheries - in particular in-lake fisheries, with the largest number of cases observed in sub-Saharan African inland fisheries. "Fish for sex" transactions are mostly integrated in the fishing sector, because many of the secondary roles are part of the value chain. Hence, they contribute to the economic network of the fishing industry, unlike the role of commercial sex workers, in which sexual exchanges are not a part of fishing-related transactions.

“Fish-for-sex” transactions occur mainly in the context of gender inequity and
impoverishment, therefore are influenced and characterized by both sociocultural and socioeconomic dimensions. Sociocultural factors include the low status of women in society, subordinate role of women in the family, and cultural norms and values regarding sex, which may contribute to women being forced due to circumstance or coerced due to lack of power to exchange sex for fish. Economic factors recognize the leverage that “fish-for-sex” offers such as reducing transactional costs in securing fish supplies in uncertain and competitive markets. Therefore, women may exert agency in transactional bargaining, such as maximizing economic benefit from sexual networks. However to underscore, these transactions occur within the context of significant gender power imbalance and socioeconomic inequities, in which women may have less power to negotiate the conditions of the transactions. Therefore, sociocultural and socioeconomic dimensions are not mutually exclusive, instead they have significant overlap in how “fish-for-sex” transactions are negotiated and practiced.

In the context of Lake Victoria, “fish for sex” transactional practices reinforce the spread of HIV/AIDS, since most of these exchanges involve unprotected sex in which both parties are at risk. Yet despite the mounting evidence, policy responses to address the heightened risk fishing communities face have been limited and fragmented. Key national and international fishery policies have historically not mentioned HIV/AIDS until recently in 2005. The neglect of fishing communities, such as in national development policy regarding poverty and social services, often means that these communities are also unable to cope with the impact of AIDS. To highlight, fishing communities living in poverty are unlikely to benefit from access to antiretroviral therapies due to their social marginalization and extensive migration. Furthermore, HIV positive persons and affected households often lack support to help mitigate the spiraling effects of the illness and larger epidemic.

**Socioeconomic impact of illness**
The heightened risk and vulnerability faced by fishing communities is two fold: first, are the characteristics of the fishing trade and livelihoods, and second, is the neglect of underlying factors that contribute to HIV/AIDS. Two main priorities highlighted by the United Nations Millennium Development Goals is eradicating extreme poverty and hunger, and combating HIV/AIDS. These two priorities are interrelated, both influencing the vulnerability to and the severity of degree to which the other is effected.

Conceptual frameworks have illustrated the increased vulnerability to HIV/AIDS that results from food insecurity and the reciprocal negative effect of food insecurity on the health of HIV-positive persons and affected households. The 1996 World Food Summit held that food security represents “a situation that exists when all people, at all times, have physical, social and economic access to sufficient, safe and nutritious food that meets their dietary needs and food preferences for an active and healthy life.” The HIV/AIDS epidemic is occurring in populations were malnutrition is already endemic. Food insecurity is a leading cause of morbidity and mortality in sub-Saharan Africa. It has inextricable linkages to the HIV epidemic. Studies from Kenya and Uganda have found that the vast majority of people living with HIV/AIDS are moderately or severely food insecure.
Food insecurity and HIV/AIDS are related through nutritional, mental health, and behavioral pathways. Malnutrition, both in macronutrients and micronutrients, contributes to immunologic decline, increased HIV-related morbidity and mortality, and heightened vertical and horizontal transmission of HIV. Furthermore, people living with HIV/AIDS have lower levels of social support and greater levels of internalized HIV-related stigma, which have been shown to be strong predictors of food insecurity. Food insecurity can further lead to feelings of depression, deprivation, helplessness, shame, and humiliation. Poor mental health status has been shown to contribute to a wide range of worsened HIV-related outcomes, including AIDS-related mortality. In the context of poverty, socioeconomic disenfranchisement can result in the inability to procure food in socially or personally acceptable ways, which contributes to risky sexual practices and heightens vulnerability to HIV acquisition and transmission.

A 2004 review on the economic burden of illness documented that household capacity to cope with HIV/AIDS may be undermined due to HIV stigma related social exclusion, weakened support networks, and deteriorating community resources, often because so many households have been affected by the disease. HIV/AIDS has exerted significant influence on rural livelihoods in sub-Saharan Africa. It has diminished rural workforce capacity, agricultural productivity, and transformed the structure of rural household and communities. Widespread AIDS-related mortality has distorted population dynamics, decreasing the percentage of working adults and shifting the burden of household responsibilities to other members, such as grandparents taking care of orphans. It has further strained the already fragile relationship between livelihood and ecological systems, since increasing socioeconomic stressors may lead to irresponsible and unsustainable production practices. Many among the rural poor have adopted ill-managed practices to increase crop yield and to generate revenue. Rural populations are dependent on both land and labor, and the consequences of HIV have altered structures of both. Furthermore, changing population dynamics and increasing stress on the environment make it even more difficult to respond to escalating financial, food, and environmental pressures.

Studies examining the impact of HIV/AIDS on agricultural households reveal a downward spiral of livelihood degradation. Household income and resources often were diverted to meet the costs of illness. Labor storages occurred since time and energy were spent to recover from illness or devoted to caretaking for those who are ill. Widow and orphan headed households increased. Subsequently, there were losses of land tenure and assets following deaths of the household male since most cultures followed a patriarchal line of inheritance. Furthermore, the income generated by households was often consumed by health-related expenses. Thus, there was decreased reinvestment back into the household and local economy. Additionally, scarce and low resourced health facilities may be unprepared to cope with the increasing burdens of HIV/AIDS related illness. This may divert limited resources away from other vital health services, such as malaria treatment and maternal and child health. Costs related to long periods of illness and the costs of antiretroviral therapies can be very high.

The communities of Lake Victoria depend both on agriculture and fishing. Hence, individual fishers and secondary fish workers with AIDS also have declining ability to
work, and thus decreasing community workforce capacity. The ill often experience loss, stigmatization, and social isolation. Fishing households with one or more people with AIDS tend to have reduced income, spend their savings on medical care, sell their productive assets (such as fishing equipment), and are unable to infest in their future (withdraw their children from school). Hence, these effects can lead to chronic irreversibilities that deepen household poverty, exacerbate food insecurity, and heighten further vulnerability to illness.

The socioeconomic impacts of illness have altered the fundamental structures of rural life, further heightening vulnerability in times when individuals, households, and communities are less able to cope. Furthermore in the context of the triple crisis, escalating food prices occurring concomitantly with decreasing access to income have worsened poverty, food insecurity, and malnutrition for the rural poor. The poverty impacts of the 2007-2008 food price crisis have shown that the poorest households with the fewest means to cope are the hardest hit, irrespective of country, region or area where they live. With rapid food price increases, poor households adopt various food and non-food coping strategies to protect their basic needs. Food-based coping strategies include; switching to cheaper, lower quality staples (such as maize, flour), decrease intake of more expensive, higher quality non-staple foods (such as meat, eggs), reduce overall food intake (such as skipping meals, reducing portions), and modify intra-household allocation of resources. Women often act as a buffer for the family by eating less and by providing quality food for their husbands and children. This may lead to detrimental effects on the woman’s own nutritional status and her child’s if she is pregnant. Furthermore, female-headed households suffer a larger proportional decline in welfare than male-headed households. This may be due to the lower level of poverty they live in and the higher proportion of income they spend on food. Non-food coping strategies include migrating in search of work, selling productive assets, reducing spending on other needs (such as education, health care, water and sanitation). These coping strategies can have potentially devastating long-term impacts that perpetuate the intergenerational transmission of poverty. Therefore, the magnitude and severity of poverty, food insecurity, and malnutrition experienced by poor households depends on their ability to adapt and the coping strategies they adopt.

Social support in remote, rural settings
Globally, HIV/AIDS disproportionately affects the most marginalized populations living at the precarious intersection of impoverishment, social disconnectedness, and disempowerment. For the marginal communities of Mfangano, multiple, intersecting socioeconomic challenges have intensified the inequities and vulnerabilities already faced. How social support is shaped and navigated given this broader context significantly influences community health. Furthermore, these upstream determinants influence how social support takes shape in response to crisis. Theorist Emile Durkheim’s defining work on the relationship between society and health found that large-scale economic or political societal crisis in times of rapid social change and turbulence have profound effects on health, such as mental health and suicide. In crisis situations, social structures are weakened, deregulating values, beliefs, and general norms that guide behavior. Furthermore, structural shifts in laws, policies, institutions,
or social environment can influence the networks and norms that shape the context of health and the community response to such changes. Social network theory arose in the mid-1950's to analyze relationships among people based on the network's structural properties, rather than based on traditional boundaries of kinship, class, etc. Network analysis thus focuses on the characteristic patterns that exist between actors embedded in a social system rather than the characteristics of the individual actors themselves. It seeks to understand the structure and composition of the network, and also the resources and opportunities that are mobilized within the network. Social network theory hence poses that the social structure of the network itself is largely responsible for determining individual behavior and attitudes. Furthermore, social support networks may directly influence many disease outcomes because these social conditions also influence susceptibility to disease.

Throughout the 1970s and 1980s, a series of studies consistently showed that the lack of social support predicted mortality from almost every cause of death. The power of these measures to predict health outcomes is indisputable, however, the interpretation of what these measures actually measure has been debated in the subsequent years. A second wave of research focused on the qualitative aspects of social relations rather than the structural aspects of social networks. Yet despite the prolific contribution to the understanding of the rich complexity of social support, there was lack of consideration of and connection to the broader context and structural underpinnings that influence how social support is shaped. Theorist Lisa Berkman and colleagues proposed a cascading framework from the macro-social to the psychobiological process that shapes how social support influences health. It starts with recognizing that social networks are embedded in larger social, cultural, and economic contexts that condition their structure. Then the characteristics of the networks influence how resources and opportunities are mobilized, and thus shape social and interpersonal behavior. By understanding social networks in a continuum of causation, the theoretical framework integrates "upstream" macro-social determinants with the social mechanisms that influence individual and community behavior.

The benefits of social support are often understood through the framework of social capital, which shapes the quality and quantity of social interactions. One of the leading writers in the field, Robert Putman, frames social capital as "connections among individuals – social networks and the norms of reciprocity and trustworthiness that arise from them... most powerful when embedded in a sense network of reciprocal social relations." In his work on civic virtue, he emphasized that interaction enables people to build communities, to commit to each other through relationships of trust and tolerance, and to weave an integrated social fabric, which benefits the community as a whole. Other leading thinkers who developed the theoretical understanding of social capital include Pierre Bourdieu in 1983 who framed it as "the aggregate of the actual or potential resources which are linked to possession of a durable network"; and James Coleman 1994 who characterized social capital as an aspect of social structure, which "facilitate certain actions of individuals who are within the structure." Even the World Bank has highlighted that "increasing evidence shows that social cohesion is critical for societies to prosper economically and for development to be sustainable."
Social support influences health outcomes based on the structure and function of its networks that provide opportunities for support, influence, social engagement, and access to material needs. Social support is usually divided into subtypes which include emotional support (nurturant feelings, such as love and caring), instrumental support (assistance with tangible needs, such as obtaining food and paying bills), appraisal support (help in decision-making and provision of feedback) and informational support (assistance with advice or information). Furthermore, social relationships provide a basis for intimacy and attachment. Strong relationships among individuals foster strong bonds to both place and community.

Social support is a dynamic interaction influenced by the interplay of altruism, reciprocation, negotiation, and obligation. It has both structural and cognitive properties, the first in which determines the characteristics and functions of social networks and the later in which influences levels of trust, solidarity, reciprocity, and participation in collective action. Relationships governing social support have valence, meaning that they can be positive, intimate, nurturing, and supportive or they can be negative, hostile, demeaning, and exclusionary. Social relationships can serve as protective exchanges, and yet negative consequences can ensue if social relationships change or become maladaptive. Even large and dense networks or settings with high levels of support have been associated with poorer health outcomes and less adaptive behaviors, such as in the transmission of HIV.

Social support has a complex, nuanced relationship with HIV risk and transmission. On one hand, it can be protective and serve to generate effective collective responses to the epidemic. On the other and, it can increase vulnerability through how its networks are structured. Cultural practices that may have served protective roles have instead become a contributor to high HIV risk and infection. One such practice is wife inheritance, an "honorable promise" in which a designated male family member of the deceased assumed responsibility for the widow and her children. However, in a region of such high HIV prevalence, inheritance patterns may influence the transmission and acquisition of HIV, such as an HIV-positive widow transmitting it on to her new inheritor with or without his knowledge. The prevalence of HIV among widows has been shown to be exceptionally high. Estimated HIV prevalence among widows in Kenya was 30.2% in 2003, and 43.1% in 2008/9. Widows in general have heightened risk for infection, and this may be attributed to inheritance or other coping strategies to survive. Furthermore, expanding social networks may increase vulnerability to HIV infection, especially in the context of impoverishment existing concomitantly in an environment where transactional sex networks are common.

In Mfangano, with one of the most concentrated prevalence of HIV/AIDS in the world, the disease has been viewed as a 'chira' in the DhoLuo language, a wasting away of not only the physical body, but of social order and cohesion; "metaphor for the moral breakdown of society", "symptom of modernity which is perceived as ill." Those infected often are accused of transgression, and thus HIV-related stigma has a negative influence on levels of social support. Furthermore, AIDS can have divisive impacts, such as reducing trust and social cohesion and therefore the capacity for collective efficacy. Strong community relations, characterized by mutual support, reciprocity, and collective mobilization have been linked to lower levels of HIV risk. High levels of illness undermine commitment to the collective action.
For social support to be health promoting, it should facilitate reciprocity and community support, solidarity in response to a crisis event, and participation in collective action. These attributes of network structure work to enhance collective competency and efficacy. Furthermore, social support should provide both a sense of belonging and intimacy among the community. Affiliative and nurturant social relationships are essential for health and well-being throughout life, especially during times of crisis and distress. Disruptions of social connections are among the most stressful events people experience. Consequently social isolation is a major risk factor for broad-based morbidity and mortality, and has been linked to higher death dates, higher sickness rates, and lower rates of survival of disease.

**Barriers to HIV prevention, testing, and treatment**

The communities of Mfangano are at heightened risk for HIV/AIDS morbidity and mortality and related adverse outcomes, and yet their socioeconomic context reinforces the barriers that prevent them from improving their health and well-being. The risks of HIV status disclosure often outweigh the benefits of seeking help, services, and care. Individuals and households are embedded in a complex network of relationships that defines their social capital, status, and participation. Thus, disease is framed and understood within their social context. HIV continues to be heavily stigmatized in most of sub-Saharan Africa. This stigma can lead to decreased social support in communities where such support is often the most critical resource in low resource settings. To highlight, HIV related stigma has been linked to increases in food insecurity, thus threatens to perpetuate the cycle between food insecurity and HIV/AIDS in communities who already are food insecure.

Stigma remains a major barrier to effective response to the HIV/AIDS epidemic, impeding access to prevention, care, and treatment services. In 1987, Jonathan Mann, the founding Director of the World Health Organization’s Global Program on AIDS articulated that stigma, discrimination, and denial of such factors were as “central to the global AIDS challenge as the disease itself.” Yet underlying the universality of stigma and discrimination is the incredible complexity and diversity of construction and experience across social, cultural, economic, and political contexts. This especially holds true for sub-Saharan Africa in which a rich diversity of cultures exists among various countries.

Stigma is a label of "deviance" or "difference," and often compels stigmatized individuals to view themselves as “disgraced” or “discredited”, and for others to reinforce this categorization of inferiority. Stigma is not a fixed attribute of an individual, instead it is a social process in which social exclusion is constructed. It is based on social relationships that navigate dimensions of power and control, hence it is not simply an outcome of individualized behavior. Structural conditions enable stigma-based discrimination, perpetuating further inequity among stigmatized groups. This social production establishes how difference is organized and dealt with to maintain social order.

Global socioeconomic transformations have created new forms of exclusion, which reinforce or exacerbate existing inequities, such as the increasing feminization of...
poverty. The HIV/AIDS epidemic developed during a rapid globalization linked to a radical restructuring of the world economy. These transformations involved drastic processes that perpetuate social exclusion which concomitantly intensified interactions with other inequities. Multiple, yet interacting factors - based on gender, race, ethnicity, religion, class, among others - have complex interplay on how culture, power, and difference shape stigma and discrimination. Socioeconomic determinants play an ever-increasing role in the social processes that construct and enforce social identity, order, and exclusion.

Because HIV/AIDS affects nearly all aspects of rural life, from workforce capacity to household structure, increasing HIV/AIDS awareness and overcoming stigma are imperative to catalyze reform and ultimately improving health and well-being. HIV testing is considered the primary gateway to both prevention and treatment services. The Kenya Ministry of Health has reported that HIV testing has more than doubled in Kenya between 2003 and 2007, however, over 80% of Kenyans living with HIV are estimated to be undiagnosed in 2007. This is in part due to prevailing stigma and discrimination, often impeding timely access to care and services. On Mfangano, based on a 2010 health and demographic survey, 9 out of 10 respondents have been tested for HIV/AIDS; however, 2 out of 3 will keep their HIV status a secret from others. Psychosocial dimensions shape how HIV/AIDS is perceived, experienced, and acted upon at individual, household, and community levels.

Furthermore, studies have also demonstrated the high rate of loss to follow-up of HIV positive patients before and during the initiation of antiretroviral therapy in low-income settings. The rate of loss between diagnosis of HIV infection and initiation of treatment can be as high as 80%, and has been attributed to access barriers (distance to clinic), poor health infrastructure (weak referral linkages to next steps of care), and high death rates of HIV positive individuals (treatment non-adherence, delay in seeking care).

With the paradigm of “treatment as prevention”, current HIV strategies advocate for testing and treating individuals as early as possible to prevent further HIV infection and transmission. In order for these new interventions to be successful, individuals would need to feel safe and supported in seeking care and services. The risks of status disclosure need to be minimized to reduce stigma, discrimination, and ostracism. Furthermore, the integration of multifaceted aspects of care, such as food programs and social support, would help ensure comprehensiveness and continuum in community health. In recent years, new priorities have emerged to address upstream socioeconomic determinants that impact health. These strategies now focus on the most salient and pressing issues that heighten risk for HIV infection and related morbidity/mortality, such as poverty and food insecurity.

II. Introduction to Research

Given the paucity of research that examines health on Mfangano, the proposed exploratory research study aims to generate theory about community perception, specifically examining the intersection of HIV and socioeconomic factors impacting community health. The HIV/AIDS epidemic has had reverberating impacts on every
aspect of rural life, and yet stigma and discrimination remain as one of the major barriers to HIV/AIDS care, treatment, and prevention. Yet despite the universality of stigma and discrimination, such constructs are characterized by the incredible complexity and diversity of experience across different sociocultural contexts. Exploratory research can elucidate how meaning is socially constructed to frame community understanding of health and well-being.

The methodological approach for the proposed qualitative study is grounded theory involving principles of community based participatory research. The study is exploratory and hypothesis generating, and aims to answer the following questions:

- What are the community perceptions of the intersection of HIV and socioeconomic factors impacting community health on Mfangano Island?
- What are the networks of socioeconomic vulnerability faced by the community and how do they interact?

The specific aim of the study is to elicit understanding of community perceptions. Through a participatory approach, the research process serves as a means to generate theory as well as to engage participants in creating awareness and understanding of the socioeconomic determinants that impact community health.

Delineating context: cultural & linguistic considerations
Mfangano Island is rich with unique cultural and linguistic traditions. Languages spoken on the island include the official languages of Kenya, Kiswahili and English, as well as the preferred languages spoken by the communities, DhoLou (also known as Luo) and Suba. Mfangano is one of the last strong and functioning Suba speech communities in the world, and these communities have integrated and intermarried with the region’s main ethnic group, the Luo, for over thirteen generations.

As documented by the U.N. Educational, Scientific and Cultural Organization, the Suba language is spoken by the Suba ethnic group, and is considered a seriously endangered language. In some communities, the Suba language and culture is even considered extinct. There are approximately 119,000 Suba speakers to date, of which most reside in Kenya. The youngest speakers have reached or passed middle age. Mfangano Island is considered a strong area, where there is a strong and functioning Suba speech community throughout. Mfangano’s Suba communities represent the eastward migration of the Abakunta clans from present-day Uganda.

In Kenya, the majority of Suba speakers use Luo as a second language. English, Kiswahili, and Luo slowly began to gain dominance and have undermined the Suba language and culture. Many Suba speakers became multilingual or bilingual in Luo. Others began loosing the ability to speak their native language. Due to socioeconomic and political pressures at the local, national, and international levels, Suba speaking parents have made deliberate decisions not to pass on the Suba language on to their children. However, recent revitalization efforts have sprung from the Suba community, whom are resisting assimilation pressures from the dominant languages and cultures. In 2000, the Abasuba Community Peace Museum on Mfangano Island was constructed to honor the Suba communities’ cherished, yet engaged cultural
heritage. It houses the Suba translation of the Bible, a proud community undertaking.

Like the Suba communities, the Luo also migrated to Mfangano Island. The Luo ancestors were pastoral nomads, and traveled south from Sudan, first settling in central Uganda then forced southeast towards Kenya during the end of the 15th century A.D\textsuperscript{131}. Through forced assimilation, the Luo adopted western style education, language, and culture\textsuperscript{129}. They played a pivotal role in the struggle for Kenyan independence. They have a prominent political, economic, and social presence in Western Kenya\textsuperscript{129}.

The Luo language is spoken by over 4.2 million people\textsuperscript{132}, approximately 13.8% of the Kenyan population that reside on the eastern shores of Lake Victoria, specifically Nyanza province\textsuperscript{129,130}. The Luo are the second largest ethnic group in Kenya, following Kikuyu\textsuperscript{139}. Outside of Kenya, over 200,000 people speak Luo, mainly in Tanzania near the Kenyan border\textsuperscript{129}.

As a language, Luo does not have official status in Kenya or Tanzania, nor is it lingua franca\textsuperscript{129}. Language use is in everyday activities, such as at the markets. Because it is not official, it is not a language of instruction at schools\textsuperscript{129}.

**Philosophical orientation to Grounded Theory**

Based on the pioneering work of Barney G. Glaser and Anselm L. Strauss, grounded theory was developed as a comparative methodology to generate theory from data\textsuperscript{133}. It builds theory by striving to understand what arises from data, how various data elements interact, and what can be conceptualized with the data findings. Furthermore, this discovery is context and time specific, meaning how the data is interpreted is embedded within the context and period it arose from. Every methodology stems from an epistemological framework of knowledge, and the philosophical orientation to grounded theory originated from the integration of Symbolic Interactionism and Pragmatism\textsuperscript{134}.

Theorist Herbert Blumer proposed three core principles in symbolic interactionsim\textsuperscript{135,136}. First is the principle of meaning, in which people act towards things (such as objects, people, or ideas) based upon meanings that they have attributed to them. Second, the principle of social interaction, in which meaning arises from the process of interaction among people. Lastly, the principle of interpretation, in which people interpret meaning and subsequently the use of meaning to inform action\textsuperscript{133}. The human world is a social, thus meaning is socially constructed\textsuperscript{137}. Human interpret and define experience, not simply passively reacting to it. How humans respond to a situation is through the symbolic meaning they attribute to experience. And it is this symbolic meaning that grounded theorists are trying to understand - how meaning is constructed, why is it constructed, and in what context is it constructed. Knowledge is an active process – “we invent concepts, models, and schemes to make sense of experience and, further, we continually test and modify these constructions in light of new experience\textsuperscript{132}.” In the domain of health, the social constructionist approach to illness is routed in the conceptual distinction between disease (the biological condition) and illness (the social meaning of the condition)\textsuperscript{138,139}. Sociocultural systems shape the meaning of illness, which may not be derived from the nature of the illness itself\textsuperscript{137}. The social construction of illness influences how people come to understand and live with their illness\textsuperscript{137}.
Furthermore, symbolic meaning shapes how society responds to those who are ill and influences the response to that illness. Additionally, information about illness is influenced by who develops and distributes knowledge.

From a complementary perspective, theorists George H. Mead and John Dewey viewed knowledge as arising from the social adaptation of humans to its environment, known as pragmatism. It is a naturalistic approach to the theory of knowledge, in which knowledge is viewed as a product of social processes in response to the environmental changes, in parallel to Darwinian theory of evolution. Dewey shares that “all reflective inquiry starts from a problematic situation,” and acquired knowledge works toward useful practice. Hence, knowledge is pragmatic and instrumental - it serves to inform action. Action is the application of acquired knowledge, and both action and knowledge contribute into each other. “Knowledge leads to useful action, and action sets problems to be thought about, resolved, and thus converted into new knowledge.” Hence, inquiry and practice is continual and cyclical. Pragmatists underscore that the construction of experience is an ongoing process embedded within a larger context, as a social interaction between humans and as an adaptation with the environment. Mead emphasizes that acquired knowledge arises from social interaction that determines how humans respond to environmental conditions faced. Thus, it is not simply the environment that conditions human response, instead humans socially construct how they respond to the environment. Humans interact with others to attribute symbolic meaning to experience, and such interactions inform the actions taken in response to the environmental conditions faced.

**Community based participatory research**

The philosophical basis for grounded theory illuminates the social interactions that shape symbolic meaning as well as the instrumentality of knowledge that informs action. Hence, community based participatory research (CBPR) can further enhance research by ensuring active participation of community partners and fostering a community-driven research process that transforms the community to take action. CBPR is defined as “a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings.” CBPR begins with a research topic of importance to the community, has the aim of combining knowledge with action, and works to achieve social change to improve health outcomes and eliminate health disparities.

Central to CBPR is equitable community participation in the research process. Studies have continuously shown that health disparities remain pervasive and persistent, and have been associated with sociostructural factors of exclusion, such as poverty, racism, lack of access to health care, among others. Therefore, marginalized communities should be fully engaged as partners in exploring and in taking action to address the health and social problems about which they – not experts as outsiders – care most deeply. The CBPR process allows for negotiation of a mutual agenda between communities and researchers that helps to frame health issues appropriately in the context of the community.

Community partners hold the expertise about the local context, culture, and language. They can help elucidate the meaning of research findings, identify priority areas to
address, and potential strategies for action\textsuperscript{147}. Community participation allows new areas of inquiry to emerge and elucidates key perspectives and nuances that researchers were not able to foresee\textsuperscript{148,149}. CBPR facilitates understanding of a wide array of experiences and building knowledge grounded in real-world patterns, rather than beginning the inquiry process with a preconceived notion of what is occurring. Participatory research can help identify key concepts and themes that capture the diversity and complexity of the communities’ lived experience. Community participation facilitates both the awareness and recognition that places community needs and priorities at the very center of the research work.

CBPR is unlike “traditional” approaches to research because it upholds that the research process should be a transformative process that empowers communities involved. It not only critiques power and resource inequities within partnerships, it also focuses on how these relationships can be transformed. Involving all members of the partnership in the research process can strengthen community capacity building and increase knowledge acquisition. CBPR emphasizes the reciprocal transfer of knowledge, skills, and capacity among all partners involved to enhance shared understanding of the underlying conditions that contribute to health and disease. CBPR facilitates knowledge transfer about what the research means, not just simply the description or dissemination of data. Knowledge transfer includes not only skills on how to conduct research, but conceptual frameworks guiding the research as well. As an example of reciprocal knowledge transfer, academic researchers can learn more about the social context of HIV on Mfangano Island and about cultural protective factors that foster community resilience in face of such a devastating disease. For community members, participants can learn more about research methods and ecological models that frame health and illness in broader contexts of public health. A participatory research process ensures community partners are involved to understand the impact of such research on the community. Community transformation is crucial in addressing the fundamental inequities that underline many health disparities.

**Research into action**
Understanding the extent and severity of certain health issues may overwhelm and even paralyze communities, whom may perceive a devastating, epidemic health issue such as HIV/AIDS as insurmountable. Therefore, the CBPR process “explicitly recognizes and seeks to support or expand social structures and social processes that contribute to the ability of community members to work together to improve health\textsuperscript{150}.” The process integrates and balances knowledge generation with community action to address the concerns of the community involved and to develop priorities actions forward. The process of research and action is iterative; “information is gathered to inform action, and new understandings emerge as participants reflect on actions taken…ongoing feedback of data and use of results to inform action are integral to this approach\textsuperscript{151}.” Furthermore, participatory ownership of knowledge is acknowledged throughout this process and transformation of the community is facilitated. CBPR can ensure “that bridges are created and trust built between community stakeholders, research is authentic to community experiences, research questions are relevant, research design and methods are culturally and educationally appropriate, knowledge is incorporated into action based upon the lived experiences of community members, research is translated into informed policy, and infrastructure is built to promote
successful implementation and longer-term sustainability. The proposed qualitative research study on Mfangano community health can help inform further research and program development that incorporates valuable community insights, feedback, and suggestions. Participatory engagement would allow Mfangano communities to shape the goals of research and programs in ways they feel are most important to address.
I. Introduction

Mfangano Island lies in the eastern part of Lake Victoria, and is a part of Kenya’s lake province, Nyanza. The lake region is characterized by an exploitative, globalized fishing industry, which has been linked to extensive population migration, practices such as transactional exchanges of “fish-for-sex”, pervasive food insecurity and malnutrition, entrenched impoverishment and underdevelopment, and natural resource degradation. These factors have been further linked to a HIV prevalence of greater than 40% in the region.

In 2006, the U.N. Food and Agricultural Organization released a policy report summarizing the impact of HIV/AIDS on fishing communities throughout the world. Based on research in the last decade, it became evident that in many fishing communities in the developing world, fishermen suffer from HIV prevalence rates often 5 - 10 times higher than the national average rates of the general population. This heightened risk and vulnerability among fishing communities stems from the structure and dynamic of the fish trade and lifestyle that leads to the catastrophic convergence of several risk factors.

The transformation of Lake Victoria into an export-oriented fishery not only permanently altered its ecosystem and surrounding livelihoods, but also led to profound impacts on the lives of its indigenous people. Hundreds of thousands of people from all over East Africa migrated to capitalize on the new fishing industry. The high mobility of fishermen and their extensive time spent away from families and communities have led to the deterioration of family and social norms that guide sexual behavior. Moreover, the sexually active demographic profile of the fisherman is characterized by sub-cultures of risk-taking and what has described as “hyper-masculine” behavior. Their disproportionally high cash income in the context of widespread impoverishment and gender inequity has contributed to widespread transactional sex exchanges of “jaboya”, commonly known as ‘fish-for-sex’.

Lake Victoria’s fishery prioritized an asymmetrical distribution of resources that has led to among the highest levels of malnutrition in Kenya despite the fact that the lake has been documented to yield up to 85% of Kenya’s total fish supply. Fishing communities consume very little of what they harvest and have no access to supplementary sources of protein. To highlight the disparity on Mfangano, food insecurity was universal among people living with HIV/AIDS (PLWHA), with levels higher than reported in other parts of sub-Saharan Africa. Furthermore, Kenya’s lake province, Nyanza, remains one of the most impoverished regions of the country, a reality that is reflected in other lakeside regions of neighboring countries. Although income from the fishery has increased over the years, its distribution had become increasingly more inequitable given the structure of the export-oriented fishing industry. Furthermore, as the life-line for its communities, Lake Victoria is now characterized by overexploitation, ecosystem degradation, and diminishing fish supplies following escalation of fishing pressure, with significant socioeconomic implications.
HIV prevalence in the Lake Victoria region
Nyanza province has the highest HIV prevalence in Kenya (15.3%), with more than twice the national HIV prevalence (6.3%)\textsuperscript{175}. Suba is one of the most marginalized districts in Nyanza, and has the highest HIV prevalence in the province, peaking at over 40\% in the early 2000’s\textsuperscript{175}. Most recently in 2010, prevalence was documented to be over 20\%\textsuperscript{175}. Mfangano is a continental island of Lake Victoria, and has been one of the five divisions of Suba district until 2012, in which it was redistricted as a part of the neighboring Mbita district (Republic of Kenya Legal Notice No. 14). Mfangano is both geographically and socially marginalized from the Kenyan mainland, accessible only by boat for local communities\textsuperscript{179}. In Kenya, Mfangano is home to the largest population of the ethno-linguistic group, the Suba; the Suba language being a seriously endangered language\textsuperscript{176}.

Given the paucity of research that examines health on Mfangano, this exploratory study aims to generate theory about community perception of the intersection of HIV and socioeconomic factors impacting community health. The HIV/AIDS epidemic has exerted effects on nearly every aspect of rural life\textsuperscript{177}, and resulting stigma and discrimination remain major barriers to HIV care, treatment, and prevention. Underlying the universality of stigma and discrimination is the incredible complexity and diversity of experience across different sociocultural contexts\textsuperscript{178,179,180}. New research designs are needed to generate theory as well as to engender community-based empowerment. The study’s participatory research process was designed to engage with the communities in partnership to understand their social construction of HIV in the context of larger socioeconomic determinants.

This hypothesis-generating study aims to elucidate how marginalization shapes community perception of HIV care, treatment and support. Mfangano’s geographic marginalization has significant interactions with socioeconomic marginalization (poverty, food insecurity, lack of institutional support, so forth), and thus, the broader term of “marginalization” will be used to encompass these interrelated dynamics.

II. Methods

Study background
The University of California, San Francisco (UCSF)-University of California, Berkeley (UCB) Global Health Framework Program sponsored interdisciplinary student teams to conduct a two part, mixed-method quantitative and qualitative baseline study on Mfangano community health. The Framework Program was funded by the National Institutes of Health/Fogarty International Center, in partnership with the Kenya Medical Research Institute (KEMRI) and Organic Health Response, a U.S. based nonprofit organization working in collaboration with the Mfangano community-based organization Ekialo Kiona. In Summer 2010, the first student team initiated a household health and demographic survey distributed among three villages on Mfangano (Mala Masa, Kitenyi, and Kitawi). In Summer 2011, the second student team, of which I was a member, prepared and facilitated a qualitative focus group study designed to understand key themes from the quantitative study conducted the year before. Three themes were selected for further qualitative research: 1) Social Support, 2) Food, Income, and Environment, and 3) HIV/AIDS Attitudes and Behaviors.
Ethics
Ethical approval for this research was provided the KEMRI Ethics Review Committee (Protocol No. 1826) and the UCSF Institutional Review Board (Study No. 10-00688) with UCB reliance on UCSF (Reliance No. 137). Written informed consent was obtained before each focus group session.

Sample selection
Twelve focus groups were organized by random sample from the three Mfangano villages. A list of households prepared for the quantitative study was used as the sampling frame. Trained female community health workers visited and recruited one eligible individual from each household that was selected. Two community health workers for each of the three villages participated in recruitment. Inclusion criteria for eligible study participants included being older than 18, fluent in the language of study (Dholuo), and not having any disability that would interfere with participation in the study (such as loss of hearing).

In addition, a total of five community members were recruited directly at the Ekialo Kiona Center during focus group sessions with low participant turnout (participants were from the neighboring Wakinga village). The same inclusion criteria applied.

Table 1. Characteristics of Community Participants interviewed* (n =105)

<table>
<thead>
<tr>
<th>Demographics of all community focus group participants</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Women (52 women)</strong></td>
</tr>
<tr>
<td>Age (years)</td>
</tr>
<tr>
<td>19 – 75; mean 33.6</td>
</tr>
<tr>
<td>Household Size</td>
</tr>
<tr>
<td>2 -17; mean 6.1</td>
</tr>
<tr>
<td>Level of Education</td>
</tr>
<tr>
<td>Range: no schooling to completed secondary</td>
</tr>
<tr>
<td><strong>Men (53 men)</strong></td>
</tr>
<tr>
<td>Age (years)</td>
</tr>
<tr>
<td>18 – 79; mean 37.5</td>
</tr>
<tr>
<td>Household Size</td>
</tr>
<tr>
<td>1- 15; mean 5.7</td>
</tr>
<tr>
<td>Level of Education</td>
</tr>
<tr>
<td>Range: some primary to completed college / trade certificate</td>
</tr>
</tbody>
</table>

Lastly, community service providers from the Ekialo Kiona Center and the Family AIDS Care and Education Services clinic, a CDC/PEPFAR-funded collaborative program of the Kenya Medical Research Institute and the University of California, San Francisco, participated in separate, researcher-led focus groups conducted in English.

Data collection
Ten staff members were hired from the community, with equal representation ensured among female and male staff. The community staff were trained in research ethics, methods, processes, and their respective roles and responsibilities. Moderators were trained to lead the focus group sessions; one moderator was trained for each of the three specific topic themes. Note-takers were trained to transcribe and record the focus group sessions, and participated throughout all the three topic areas. Staff were
bilingual in English and DhoLuo, and served as a cultural and linguistic bridge between the predominate language of the community, DhoLuo, and the language utilized by the research team, English.

**Table 2. Composition of Staff Focus Group Roles**

<table>
<thead>
<tr>
<th>Female Staff</th>
<th>Male Staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 Moderators (one for each topic theme)</td>
<td>2 Note-takers</td>
</tr>
<tr>
<td>3 Moderators (one for each topic theme)</td>
<td>2 Note-takers</td>
</tr>
</tbody>
</table>

**Total: 10 Community Staff (5 female staff; 5 male staff)**

In-depth moderator guides for each theme were developed by the research team, and reviewed with the community staff for cultural and linguistic appropriateness and context specific relevance. Community staff (moderators and note-takers) led gender-based groups in the three topic areas, moderated in DhoLuo. Two female groups and two male groups were conducted each week for each topic area, totaling 12 female and male focus groups over three weeks that covered the themes: 1) Social Support, 2) Food, Income, and Environment, and 3) HIV/AIDS Attitudes and Behaviors.

**Table 3. Weekly Focus Groups Themes and Topics**

*Themes and topic areas under investigation (see appendix for full moderator guides)*

**Week 1**

**Social Support**

- Types of Social Support
- Seeking Support
- Food and Support
- Jaboya (“fish-for-sex”) and Support
- Health, HIV, and Support
- Wealth and Support
- Expectations of Support
- Suggestions for Providing More Support

**Week 2**

**Food, Income, and Environment**

- Livelihoods and Income
- Food Security
- Fishing
- Farming
- Management (income, food)
- Jaboya, Food, and Environment.
- Water treatment
- Suggestions for Solutions

**Week 3**

**HIV/AIDS Attitudes and Behaviors**

- HIV/AIDS in the Community
- HIV Risk Behaviors
- HIV on Mfangano
- HIV Testing
During the weekly focus group process, the research team conducted a debrief session with community staff after each focus group. The debrief served as an opportunity to address any questions or concerns that arose from the focus group, clarify participant responses, and enhance the data collection process for the next focus group, such as correcting the moderator guide.

**Table 4. Weekly Focus Group Schedule**

<table>
<thead>
<tr>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
<th>Friday</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus Group</td>
<td>Debrief Sessions</td>
<td>Focus Group</td>
<td>Debrief Sessions</td>
<td>End of Week</td>
</tr>
<tr>
<td>Sessions 1</td>
<td>1 (Female &amp; Male)</td>
<td>Sessions 2</td>
<td>1 (Female &amp; Male)</td>
<td>Female &amp; Male</td>
</tr>
<tr>
<td>(Female &amp; Male)</td>
<td></td>
<td>(Female &amp; Male)</td>
<td></td>
<td>Debrief</td>
</tr>
</tbody>
</table>

Furthermore, the study methodology piloted an innovative model for Mfangano’s low-resource setting in which separate translation and transcription services were both time and cost-prohibitive. Each audio Dholuo focus group transcript was reviewed response by response with community staff, translation and interpretation of each response provided in English, and documented to serve as the English transcription. Separate debriefs occurred for each gender-based focus group, and the moderator/note-taker team ensured inter-reviewer correspondence by discussing and resolving discrepancies that arose during the review process. At the end of each topic week, the larger group came together to discuss key findings among both female and male focus groups. Discussion among community staff and the research team allowed for clarification about the data being collected, enhanced sensitivity and awareness of what was being asked, encouraged opportunity for interview questions to be modified or clarified, and ensured gender-specific issues were addressed and discussed. This participatory model with the community staff allowed initial analysis and synthesis to occur during primary data collection.

**Analytical methods**

**Theoretical Framework**

The study employed grounded theory to analyze data, while integrating principles of community-based participatory research. The philosophical orientation to grounded theory stemmed from the integration of *Symbolic Interactionism* and *Pragmatism*\(^{181}\). Interactionism posits that meaning arises from social interaction. From a complementary perspective, Pragmatism posits that meaning informs knowledge that works toward useful practice, such as informing action, generating ideas, and creating solutions to address challenges faced.
Thus, the philosophical basis for grounded theory integrates the social interactions that shape symbolic meaning as well as the instrumentality of knowledge that informs action. Using participatory research methods enhances data analysis and interpretation by ensuring active participation of community partners in understanding the social construction of their perceptions as well as fostering a community-driven research process that transforms the community through both knowledge generation and action. The study is exploratory and hypothesis generating. Data analysis involved two phases: preliminary analysis and participatory analysis.

**Preliminary Analysis**
First, as a preparation, student researchers, of which I was a part, reviewed the English focus group transcripts to determine the coding structure and relevant codes. Second, selected codes were applied across the three themes (Social Support; Food, Income, and Environment; and HIV/AIDS Attitudes and Behaviors) using ATLAS.ti, a qualitative analysis software tool. Third, conceptual analysis was conducted to identify, elaborate, categorize, and integrate relevant themes and conceptual schemes. Quotations, observations, and memos were brought together and evaluated throughout the preliminary process.

**Participatory Analysis**
Community health workers who participated in the baseline quantitative (survey) and qualitative (focus group) studies were engaged in the participatory analysis process to review, validate, and refine the identified themes and conceptual schemes. Since the community staff held the expertise in the local culture and context, they helped to clarify the concepts, identified gaps in knowledge, discussed how the concepts and conceptual schemes could be better organized, and probed further into issues specific to Mfangano’s marginalization. Furthermore, as female staff, the community health workers elucidated gender-specific topics and their input was incorporated to ensure gender responsiveness of the analysis process.

III. Results

The study elucidated three major socioeconomic domains that were influenced by Mfangano’s geographical and socioeconomic marginalization. Domains were organized in an ecological framework described at the individual, household, and community level. Domains, however, were not mutually exclusive and had significant interaction with each other. Furthermore, levels that encompassed larger socioeconomic determinants were not organized as separate domains themselves. Instead, these determinants, in which the communities had the least control over, were described in relation to the domains most salient and directly experienced in their lives.

The three domains include: 1) readiness at the individual level, 2) accessibility at the household level, and 3) collective efficacy at the community level.
Individual Level: Readiness

For this study, readiness describes whether a person is ready or not to know and disclose their HIV status. Readiness is influenced by the themes of HIV infection’s association with behavior, perceived benefit and risk, and encouragement.

Association with behavior
HIV/AIDS can be characterized as an unspoken disease, in which many are not ready to know or disclose their status. This is mainly due to entrenched perceptions of HIV being associated with inappropriate or immoral behavior, such as prostitution, promiscuity, and unfaithfulness.

A 46 year-old married woman describes:

“\text{When you get the [HIV/AIDS] disease, there must be a reason why you got it. The disease only depends on how you live.}”

Similarly, a 34 year-old married man explains:

“\text{[People view that] if the married are not faithful and the youths don’t abstain, then it can be considered their own fault.}”

Being “ready” means understanding knowledge of status, and the process of disclosure would initiate coming to terms with and overcoming negative self-perception (fear, guilt, shame), interpersonal perception (mistrust, misunderstanding), and community perception (transgression, witchcraft). These perceptions interact and influence how individuals internalize their HIV status, how they view others will perceive their status, and how such perceptions affect social relationships.

A 53 year-old man describes the process of status disclosure:

“\text{[Status disclosure] depends on the views of the community members, friends, and family members. Many times people are not willing to associate with people whose HIV status is positive.}”

A 46 year-old woman explains the risk of status disclosure:

“\text{It is important for people to reveal their status. Those who are afraid to reveal their status will get encouraged if they see others...They have not disclosed because they are afraid...They fear being ashamed. These are the reasons for those risks.}”

Stigma associated with behavior affects the community’s ability to empathize or sympathize with PLWHA, and consequently how the community responds to such behavior. To illustrate in contrast, when HIV/AIDS is not attributed to behavior (such as in children), there is a community perception that such persons deserve sympathy, as illustrated by a 33 year-old man:
"Children can get support because they can win the sympathy of the community and therefore can be more easily supported compared to others. Children were subjected to the illness through blood transfusion or other modes of transmission and they did not get the disease through their behavior. For children, it is out of their control."

**Perceived benefit and risk**

On Mfangano, there is a growing community perception/awareness that there is a 'benefit' to status disclosure since it enables accessing HIV-related support, as described by a 40 year-old woman:

"If people know that you are HIV positive, you get more support. If you don’t tell people, nobody would know your problems and so they cannot help you."

Similarly, a 61 year-old man shares how knowledge of HIV status helps to access care:

"If one is tested and found positive, then he or she will be counseled on how to lead a better life."

However, there is also a perception that there is lack of access and resources to such support on Mfangano in comparison to the Kenyan mainland. Even if support is offered for PLWHA, it is perceived as limited and minimal, and thus not enough to make a significant impact. Consequently, the lack of access to support on Mfangano may influence perceived benefit of HIV-related support.

A 27 year-old man describes food access in comparison to the Kenyan mainland:

"In some places, like Kisumu [an urban center on the mainland], HIV positive persons are given flour to support themselves. From government or NGOs."

Similarly, a 52 year-old woman expresses the perception of limited access:

"Outside of Mfangano, people who are HIV positive get food, but not on Mfangano."

Furthermore, Mfangano’s geographic barriers inhibit timely, accessible support, as shared by a 21 year-old man:

"[It is difficult to ask for support because] the community is far from the sources of support, specifically government offices."

Thus, the lack of perceived benefits heightens the risks faced by PLWHA on Mfangano, as described by a 29 year-old woman:

"[For HIV persons], we hear that the government gives support but we are not sure because we have not received any support on Mfangano...There’s benefit
Consequently, the perceived ‘risks’ of status disclosure may outweigh the perceived ‘benefits’.
Status disclosure (to access HIV-related support) may potentially jeopardize access to other sources of community support since such support is dependent on community perception. Once an individual discloses her/his status, the perception of her/him changes, and may lead to negative effects, such as stigmatization and discrimination.

A 39 year-old woman describes how stigmatization affects status disclosure:

“[Women choose not to be tested for HIV/AIDS] because they are ashamed. They fear stigmatization.”

A 24 year-old man shares how stigma impacts accessibility of support:

“People affected with HIV have low chances of getting support because people tend to shy away and fear them because of their disease.”

As a consequence of stigma, a 38 year-old woman explains the risk of social exclusion:

“[The risk of disclosure is that] you will be lonely. You do not want to go to crowded places. Stigmatization brings about stress.”

**Encouragement**
Community participants perceive encouragement as an important type of social support in overcoming barriers and challenges to testing and status disclosure. Encouragement enhances individual readiness to seek HIV care, treatment, and support. Furthermore, persons who have been tested and have disclosed their status serve as positive role models for others in their community.

A 37 year-old woman describes the importance of encouragement in HIV care:

“[The testing] services are good. We go there when we are suggesting that we are HIV positive. But when we get the services from the VCT counselors we get encouragement and the encouragement is that we will not die soon.”

Similarly, a 46 year-old woman shares:

“Yes it is important [for people to reveal their status]. Those who are afraid to reveal their status will get encouraged if they see others.”

A 39 year-old woman describes the role of encouragement among partners:

“Nowadays people are encouraged to get tested before marriage. [When people become HIV positive], it is not one’s fault because one can get the disease without
knowing that he/she is going to get it. For example, a lady may not be HIV positive, and get married to a man who is HIV positive.”

A 29 year-old man depicts the role of encouragement in role-modeling among PLWHA:

“The type of services or support that are received by those who have already declared their status can help them encourage people who haven’t gone for testing to go and get tested so they can enjoy such benefits.”

Household Level: Accessibility

At the household level, accessibility describes household capacity to access and/or obtain social support. For this study, social support is characterized by the structures and networks that mobilize support, resources, and opportunities. Accessibility is influenced by the themes of scarcity, reciprocity, and productivity.

Scarcity

Increased scarcity has strained culturally established systems/networks of social support. Therefore, cultural values and norms that governed how the community provided a safety net in the event of crisis and adversity have been weakened, such as in the case of the provision of a safety net for the dependents like the disabled, elderly, and orphans.

A 19 year-old woman describes how lack of access to food affects food security for dependents:

“The crippled and the disabled [lack food] because they depend to get food from other people, but if those people lack food to bring to them, they will also lack food.”

Similarly, a 25 year-old woman shares the same impacts:

“An orphan will lack food if the family who she lives with doesn’t have food.”

In times of increased scarcity concomitantly with increased need, there is a community perception that it is difficult to share when there is so little, there will not be enough for one’s own household if one shares, and one can only share what one has.

A 55 year-old man explains how scarcity influences social norms:

“In the current days, people do not share food because the food is scarce. If you share it, it may not be enough for your whole family.”

Similarly, a 27 year-old man describes how households cope with scarcity:
“It is not easy for households to share food because maybe the food that a household has is calculated with time. It will last for a few days, so if they share it, they may run out in a few days.”

A 40 year-old woman depicts the complexity of cultural norms and the realities of scarcity:

“During a harvest, I can give some food to others who do not have. During a famine, we close doors so others do not get it…It is not easy to share food, but if someone comes to the house we welcome them to eat. But usually, we eat food with our children only. Some may be willing to share food but others may not be.”

Furthermore, HIV affected individuals and households may be excluded from vital social support systems/networks, thus increasing their vulnerability at a time of increased need.

As elucidated earlier the perceived risks to HIV related social exclusion, a 53 year-old male similarly describes the increased vulnerability of HIV affected households:

“[HIV positive people] get little support since most community members do not want to get close to them. So they cannot give the support readily to those with HIV. They are afraid of interacting with those with the virus.”

Similarly, a 29 year-old woman shares:

“[HIV positive people] will shy off from attending places like the church, even though the church is one of the places where one can get emotional support.”

Reciprocity
Due to scarcity, there is a community perception that relationships assume characteristics of reciprocal exchange, in other words the ability to pay back or return the favor determines what support can be asked. Scarcity raises the expectation of reciprocity, as explained by a 26 year-old man:

“Households can share food with other households but on the basis that they will return the favor.”

Similarly, a 30 year-old man describes:

“It is easy to share food with friends depending on what help they have offered in the past.”

Furthermore, the perception of the ability to reciprocate shapes the type and magnitude of support provided and sought for. There is a community perception that PLWHA are unable to work and are persistently in need of support, further elucidating the consequences of individual disease on norms of reciprocity.

A 26 year-old man describes the perceptions about the ability of PLWHA:
“Yes, there are some misconceptions such as some people tend to view HIV positive people as unable to perform their daily duties.”

A 53 year-old man depicts the perception of persistent need from PLWHA:

“Someone can be persistently asking for support and community members may get tired from his persistency.”

A 29 year-old woman describes the physical consequence of HIV at the individual level:

“[HIV affects one physically because] you will become thin and shy…You become weak and cannot involve yourself in any work.”

A 42 year-old man explains the consequences of HIV at the household level:

“When one falls sick of HIV, he will not be able to undertake his daily duties and cannot provide for his family.”

Similarly, a 37 year-old woman describes:

“HIV lowers our sources of income because we become very weak and cannot continue working.”

Furthermore, PLWHA may be at risk of exclusion from their household and from sources of support, thus heightening vulnerability a time where there is decreased ability to support oneself and one’s household, as described by a 24 year-old man:

“HIV positive persons will not be welcome by other members of the family…Some people may not be ready to continuously provide support for HIV positive persons…In cases where the breadwinner is the HIV victim, then the support that his household gets is limited.”

If, however, PLWHA regain their health and strength, then the perception of their ability may be regained. Health is a significant marker of perceived ability. However, despite perceived ability, HIV related exclusion is still a determinant in whether PLWHA have accessibility to support, as described by a 53 year-old man:

“[HIV positive people] can get enough support when they are still strong at an early age. When they are still physically strong they can still benefit from the help and in return can help others too. HIV positive people may also get little support because people tend to shy away from them.”

**Productivity**

For communities of Mfangano, the security of their livelihoods primarily relies on labor and productivity. Hence, household ability to cope with the effects of scarcity and
increasing need is largely dependent on productive household members. This is due to increased scarcity that inhibits other households from sharing with other households as well as lack of adequate provision of institutional support due to Mfangano’s marginalization. In other words, households depend mostly on their own labor and productivity for livelihood security.

For PLWHA, productivity, food security, and treatment adherence are intricately related. Community participants perceive inadequate food and nutritional intake as a barrier to treatment adherence. Lack of treatment adherence further decreases health and hence negatively impacts productivity, which heightens risk for household insecurity thus perpetuating further vulnerability.

A 32 year-old man, supporting a seven-member household, shares the positive benefit of HIV treatment on productivity:

“Those who are HIV positive, they are put on antiretroviral drugs (ARV) that is enough support for them to stay strong and give them energy to be productive so they can support their families.”

Similarly, a 27 year-old man, supporting a five-member household, describes:

“Taking drugs, such as ARVs, can make someone regain strength and make them capable of retaining his/her duties.”

A 25 year-old woman, supporting a six-member household, illustrates the positive impact of enhanced productivity:

“If I do my job without getting tired, then I will be able to provide my family with food...If I am strong I’ll do my job well and get money. First you have to eat, then you will have energy, then you will work hard to get money...When you work without getting tired, you will have enough food from your farm.”

In order to adhere to HIV treatment, there is community awareness of the importance of adequate food, as shared by a 23 year-old man and a 58 year-old man respectively:

“HIV positive people need to have enough energy before they take the medication.”

“[In concurrence], drugs are very reactive so people need to eat food before taking the medications.”

However, barriers to food access have been shared as challenges to treatment adherence, as described by a 35 year-old man:

“It is expensive to observe the diet requirements for the HIV positive patients. One’s ability to do income-generating work will be lowered.”

Similarly, a 29 year-old woman explains:
“[For HIV/AIDS treatment], you need to eat balanced diet, but there is no money to buy this food.”

Therefore, there is community understanding of the interrelated linkages between HIV care, food security, and productivity, and thus the expressed need for social support to address critical disruptions in these linkages.

A 61 year-old man describes the value of social support in HIV care:

“HIV positive patients can be supported by either their family, friends, or NGOs. Those who are on ARV drugs can still do productive work and get income.”

Furthermore, access to support has been perceived to enable individual readiness with status disclosure, as described by two women, the first a 41 year-old woman, the second whose age was not known:

“Yes, I will list my status publicly if I know that I’m going to get support.”

“Yes it does, [the amount of support impacts whether someone discloses their status]. If you know that you are going to get ARVs, you will disclose your HIV status.”

Similarly, a 27 year-old man explains:

“If food can be made available to the HIV positive people, then everyone who is positive will be ready to disclose their status and thus be able to access the food.”

Community Level: Collective Efficacy

At the community level, collectivity efficacy describes how socially cohesive and how effective the community works together and acts as a collective whole. Collective efficacy is influenced by the themes of community capacity, burden of illness, group effectiveness, and underlying inequities.

Community capacity
Communities of Mfangano rely mainly on their labor and productivity to cultivate their natural resources (farming, fishing) to ensure food, economic, and livelihood security. Participants have expressed a decreasing ability for community systems and networks to cope with the community level effects of HIV/AIDS. The epidemic has reduced the productive population due to illness and loss of lives, such as the workforce engaged in farming and fishing, as described by 40 year-old woman:

“[HIV is] increasing the number of widows and widowers. Mostly, the men die very fast, so the disease lowers the community power to cultivate in the farms and fish.”
Similarly, a 37 year-old woman explains:

“When you are a farmer, and you are HIV positive, you will not have strength to cultivate your farm.”

The changing population dynamic has had reverberating effects, especially in times of increasing scarcity concomitantly occurring with increasing need. This has interrelated consequences at the individual, household, and community levels, as described by a 42 year-old man:

“When one falls sick of HIV, he will not be able to undertake his daily duties and cannot provide for his family…[HIV/AIDS is related to poverty] because it makes one not attend to his or her sources of income.”

Similarly, a 24 year-old man shares:

“HIV is connected to our lifestyles since the main factor contributing to it is poverty…HIV may affect the person in charge of the household (breadwinner) and so may put the family members at risk because they will have no one to provide for them.”

Community exhaustion of resources and capacity due to the compounding effects of scarcity, increasing need, and lack of productive members has exacerbated the socioeconomic inequities conditioned by Mfangano’s marginalization. Therefore, there is a community perception that it is hard to overcome the community level effects of HIV/AIDS despite the expansion of HIV care and treatment over the years.

A 40 year-old woman shares the perception of helplessness:

“We do not have a healthcare facility around that can help the positive. Though they are sick, they are forced to involve themselves in very hard work…[HIV/AIDS] is a big problem that should be looked into. It is destroying our children.”

HIV affected households are more prone to cycles of poverty that depreciate household assets, as described by two women, both 37 years old.

“[HIV] lowers our sources of income because we become very weak, and we cannot continue working.”

“[HIV/AIDS is related to poverty] because people do not do their work and they spend all their wealth on treatment so you will remain poor.”

Similarly, a 26 year-old man explains:

“Money, which would have been used on the farm, is now diverted for medication for the sick.”
Furthermore, for the communities of Mfangano, what they lack in infrastructure or services, they pay for out-of-pocket, such as the need to pay teachers as well as school fees due to the lack of adequate governmental support for education. As a double burden, community members have to pay more when they have less, in comparison to the Kenyan mainland, as described by a 30 year-old man:

“The community has lack of school teachers. In [mainland] town schools, there are enough teachers, but on Mfangano there is a shortage. This forces the parent teacher association (PTA) to pay some levies (fees) to untrained teachers to teach the students.”

Furthermore, the themes of scarcity and reciprocity interact in determining what support can be asked, as described by a 30 year-old man:

“One way through which people support themselves is by asking for support from someone else. For example if one lacks school fees or food he might request a neighbor, relative, or another member of the community for it. Support is when you ask for it. You get a loan, it is borrowed so you can pay back.”

**Burden of illness**
Structural barriers to care, treatment, and services are more pronounced given Mfangano’s marginalization. Community participants expressed the lack of: access to health care, adequate health resources, transportation infrastructure, availability of treatment, and supportive services.

A 42 year-old man describes the complex interactions of multiple structural barriers:

“It is not easy to access medication. The drugs are only available at health centers, which are very far from the community. Transport to these health facilities can be a problem. Sometimes one might find drugs missing from the health facility.”

Similarly, a 27 year-old shares:

“It’s not easy [to access medications]. Some of the medicines are lacking in our stores so we are required to go and buy from the chemistry’s.”

Hence, regular access to care, treatment, and support is challenging for PLWHA, especially for men involved in the fishing trade, as explained by 24 year-old man:

“Fishing causes movement of fisherman from one place to another and so may interact with people form different backgrounds whose status may not be known and so may spread the HIV virus...Some people are doing certain jobs that will make them not be available at the time they are required to take the drugs. Some may consider carrying drugs with them is tiresome and that people will know they are HIV positive.”

In comparison, women have relatively more opportunities for HIV related care,
treatment, and support because of the integration of such services with maternity care. However, women still confront systemic structural barriers in accessing adequate health care, as described by a 38 year-old woman:

“People seek help for health problems…from hospitals, but they don’t get it. The only thing the hospital can afford to give is mosquito nets and water can.”

Similarly, a 41 year-old woman explains:

“We find it difficult to access medications. We only get them in Sena [Mfangano’s largest town], which is far away.”

At the community level, lack of care, treatment, and services has weakened entire systems/networks due to increased members who are ill and unproductive, increased expenditures on the ill, and increased time for caretaking - thus further straining collective capacity. These consequences have interrelated effects at the individual, household, and community levels.

A 39 year-old woman describes the impact of HIV on health and productivity:

“There is no income because when you are sick it is hard to go look for sources of income so you cannot get food.”

Individual illness thus affects those associated with the ill, as shared by a 79 year-old man:

“[For a household], a sick person reduces the manpower contributed to working on the farm.”

Impacts of HIV-related illness have been observed to occur throughout the community, as described by 35 year-old man:

“Yes, people will abandon their duties on the farm to look for ways of getting money to get medication for the sick.”

Similarly, as shared by another 35 year-old man:

“A lot of time [typically] for farming is in search for medication and medical services for the sick.”

Furthermore, pervasive stigma and the association of care, treatment, and support with disease have been major challenges for PLWHA, as depicted by a 38 year-old woman:

“[People are afraid of knowing their status] because they fear being stigmatized…The normal sick people have booklets. When the people are HIV positive, they have files. Normal people carry their booklets to the hospital, but HIV people have the files kept at the hospital…They are gossiped about by others.”
Similarly, a 37 year-old woman explains:

“[People default on treatment] because of the separation of the health centers, they want to avoid being stigmatized.”

This further exacerbates the burden of illness due to delay in seeking care, treatment, and support, as described by a 61 year-old man:

“Some men are shy and they just feel that when they are seen walking into a volunteer counseling and testing (VCT) center even if the result is not yet out, they will be seen as being HIV positive.”

Similarly, a 30 year-old man explains:

“For certain illness, it is not easy to ask for support for fear that your problems will be revealed to others, specifically HIV.”

Furthermore, there is a community perception that delayed testing has contributed to HIV/AIDS on Mfangano, as described by a 27 year-old man:

“[HIV/AIDS] exists on the island because members of the community develop the attitude of going for testing too late.”

**Group effectiveness**

There is a community perception that group formation increases efficacy in accessing support. Participants have shared that accessing support is easier as a group, for example obtaining institutional support such as loans, as illustrated by a 28 year-old woman:

“It is difficult [to ask for material support] if you do not belong to a certain group...it is the condition to belong to a group. [Lenders] ask what kind of work do you do to pay back the loan...Those who have no groups [experience difficulty in asking for help] because individual support is not easy. People in groups find it easier to get support.”

However, misunderstanding and misconception at the community level about HIV/AIDS have led to divisive effects, such as mistrust and conflict. HIV-affected individuals and households may have reduced capacity to tap into culturally established systems/networks of support due to increased HIV-related social exclusion. As a consequence, this may decrease how such sources of support can be mobilized for PLWHA, as depicted by a 55 year-old man:

“If one declares [his/her] HIV status it brings conflicts and misunderstandings among people. If one declares their status, those people who are close, will now distance themselves. Some people will end the relationship because they associate the disease with the workings of the devil. Disclosure does not bring good relationships. The person is an outcast of the community. This is why people keep quiet.”
Similarly, a 30 year-old man describes:

“[HIV affected] households get little support. Most people do not welcome people from these households, do not want to mingle or associate with them.”

Support groups formed for and by PLWHA are important sources of HIV-related support. Perceived benefits include: receiving encouragement and emotional support, enhancing ability to obtain material support, overcoming stigma, receiving mentorship, and increasing awareness and knowledge about HIV/AIDS.

A 24 year-old man shares the benefits of emotional support for PLWHA as a group:

“Mostly [HIV positive people] receive emotional support. And this is obtained from people of the same group. Their fellow sick, other HIV positive people.”

A 33 year-old man describes the material benefits:

“[HIV affected] households get enough support because they get free supplies and services. As a group, HIV persons get more support from NGOs but not as individuals.”

Despite entrenched fear of stigma at the individual level, a 30 year-old woman describes that the benefits as a group helps to overcome stigma:

“HIV affected households] can only get help if they belong to a support group. Nowadays, there is no stigma. If you make your status public, people will encourage you.”

Similarly, a 61 year-old man explains:

“Yes [the amount of support influences status disclosure], especially when they see those who form groups are given finance to start income generating activities, so then they will feel like they can disclose their status.”

Furthermore, enhancing awareness and collective knowledge were perceived as important benefits for PLWHA, as expressed by a 40 year-old woman:

“I would like more information about HIV/AIDS, how to protect against the HIV spread, and other supports such as food. I think it is more important if the positive are given more information on HIV/AIDS.”

Given the high prevalence of HIV/AIDS on Mfangano, almost every household has been impacted by the epidemic directly or indirectly, and thus the exceptional status and exclusion of PLWHA may decrease the capacity for the community to act as a collective whole. Although there is a community perception that working together as a group increases ability to access support, PLWHA are still perceived as a separate population, and may not be integrated in the community due to HIV-related social
exclusion. Thus, HIV-affected individuals and households may have reduced capacity to tap into community networks of support due to HIV-related social exclusion.

**Underlying inequities**
Given the advancement of HIV/AIDS care and services in Nyanza in the past decade, there is growing community perception that PLWHA in the region have entitled access to institutional support, such as food aid, employment opportunities, care and treatment, so forth. This generalized perception persists even in the context of Mfangano’s marginalization, in which actual access to such support is perceived as limited. The table below lists the types of support that community participants perceive are offered for PLWHA.

<table>
<thead>
<tr>
<th>Table 5: Community perception of types of support offered for PLWHA</th>
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<tbody>
<tr>
<td><em>Identified concepts from HIV/AIDS Attitudes &amp; Behaviors focus groups, from both female and male groups.</em></td>
</tr>
<tr>
<td>• Food support (flour, food aid)</td>
</tr>
<tr>
<td>• Employment/income generation opportunities (grants/funds, financial support, jobs, farming equipment)</td>
</tr>
<tr>
<td>• Health services (access to drugs/medicine, education/counseling services, emotional support)</td>
</tr>
<tr>
<td>• Resources (water cans, chlorine, mosquito nets, condoms)</td>
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</tbody>
</table>

Community perception of the support aid for PLWHA overlaps with the expressed needs of the community overall, such as the need for food, opportunities for income generation, health care, so forth. Therefore, the targeted and limited institutional strategies for PLWHA may not be addressing underlying socioeconomic inequities faced by the community as a whole, all of whom face similar needs and circumstances.

<table>
<thead>
<tr>
<th>Table 6: What are the biggest health problems in this community?</th>
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</thead>
<tbody>
<tr>
<td><em>Participant responses to first question of HIV/AIDS Attitudes &amp; Behaviors focus groups, from both female and male groups.</em></td>
</tr>
<tr>
<td>Poverty</td>
</tr>
<tr>
<td>Disease/Illness (e.g. malaria, gastrointestinal problems)</td>
</tr>
<tr>
<td>HIV/AIDS</td>
</tr>
<tr>
<td>Ignorance**</td>
</tr>
</tbody>
</table>

**Community staff interpreted and translated the concept of “ignorance”, which may include lack of access to education and information.**

These underlying inequities thus reduce collective efficacy in the context of Mfangano’s socioeconomic and geographic marginalization, in which both PLWHA and those living without HIV/AIDS lack the resources and capacities to address their most salient needs and challenges. As elucidated earlier, community participants have expressed that access to support is an important consideration for status disclosure since it enables
access to the resources and opportunities that address their most pressing socioeconomic disparities, such as poverty, food insecurity, and lack of access to health care.

IV. Discussion

Findings from this preliminary exploratory study elucidated how marginalization influences community perception of HIV care, treatment, and support. The impact of marginalization on community perception of HIV is described within an ecological framework at individual, household, and community levels. However, domains elucidated at these different levels are not mutually exclusive and have significant interaction with each other.

At the individual level, the domain of readiness describes the state of whether a person is ready or not to know and disclose their HIV status. This is mainly determined by the perceived benefit versus risks of testing/status disclosure. There is community awareness of HIV-related benefit with testing/status disclosure, such as institutional or governmental support. However, due to Mfangano’s marginalization, there is also awareness that Mfangano lacks access to such HIV-related support in comparison with the Kenyan mainland. Therefore, perceived risk of testing/status disclosure may outweigh the perceived benefit. Risk has been mainly described as consequences of HIV-related stigma at individual, interpersonal, and community levels. For the communities of Mfangano, the most important sources of community support may be jeopardized with status disclosure since such social support is based mainly on community perception. Community participants have shared that sources of encouragement has been helpful in overcoming barriers and challenges to testing/status disclosure. Therefore, strategies at the community level itself to change community perception of HIV/AIDS may help to enable access to HIV care, treatment, and support.

Current HIV treatment guidelines indicate that readiness should be assessed before initiating treatment to assure adherence. In one of the earliest concept analyses of readiness for nurses in AIDS care, readiness describes a pivotal awareness that a particular change will be beneficial after considerations of barriers and responsibility for action\textsuperscript{183}. In a more recent concept analysis, similarities between various readiness theories recognized that there is an initial period of emotional turmoil, then a period of indecisiveness in which benefits and risks of change are weighed, subsequently action for change is undertaken, and the maintenance of change continues over a person’s life course\textsuperscript{184}. In a 2010 review of readiness and adherence, the study revealed that there was a myriad of conceptualizations that guided the definition and measurement of readiness\textsuperscript{185}. Despite being one of the most important aspects of HIV care, the results of the review did not find a consistent definition of readiness nor a relationship between the concepts of readiness and actual behavior, such as treatment adherence. Based on prior research, readiness has primarily been assessed at the individual level\textsuperscript{184,185} (e.g. individual perceptions, attitudes, behaviors, outcomes), therefore, currently there is a gap in research in assessing how ecological determinants influence and enable readiness. None of the twenty-seven articles published between 1998-2010 analyzed community level factors that shaped readiness, such as community perception, social
support structures, collective efficacy, so forth. A more recent 2012 review of 5 HIV treatment guidelines also found no good definition, measure, or evidence that readiness predicts adherence. Current concepts view readiness as a one-time concept captured in one point in time. However, the reality is that readiness is a state of mind that is contemplated again and again over a person’s life course. Furthermore, studies have suggested that the barriers to adherence during ongoing treatment often are the same challenges that keep individuals from feeling ready to initiate care, thus revealing the relationship between the patient’s initial attitudes prior to treatment and actual difficulties in long-term adherence. Therefore, additional research is needed to characterize readiness, and to understand what facilitates and enables readiness over the course of an individual’s life within the social context they live in. In the largest study that examined readiness to enter care, cognitive state of readiness and interpersonal supportive relationships were among the most important predictors in initiating HIV care.

At the household level, the domain of accessibility describes household capacity to access and/or obtain social support. Communities of Mfangano face the compounding effects of scarcity concomitantly with increasing need, thus straining culturally established systems/networks for social support, such as caring for the most vulnerable (disabled, elders, orphans). Furthermore, social support is increasingly characterized by reciprocal exchange and not by cultural norms and values that govern how the community responds as a safety net. Community respondents shared that it is difficult to share when there is so little, that there will not be enough for one’s own household if one shares, and that one can only share what one has. Due to livelihood reliance on labor and productivity, household ability to cope with effects of scarcity and increasing need is largely dependent on productive household members. However, HIV has had significant impact on labor and productivity, thus further exacerbating the vicious cycle that perpetuates their vulnerability. Community participants are aware of the linkage of productivity, food security, and HIV treatment. However, lack of adequate support inhibits household ability to overcome these interrelated challenges that reduce household labor due to HIV-related illness, jeopardize food security dependent on such productivity, and heighten risk for treatment non-adherence due to lack of food. These cyclical effects heighten household risk faced in times of scarcity concomitantly with increased need.

In low-resource settings such as Mfangano, the consequences of illness contribute to and perpetuate impoverishment. A 2004 international review on the economic burden of illness indicated that household capacity to cope with HIV/AIDS may be undermined due to HIV stigma and related social exclusion, weakened support networks, and deteriorating community resources, often because so many households have been affected by the disease. In resource-poor areas, illness imposes high and regressive cost burdens on patients and their families. Often the costs can be catastrophic for households, especially for those affected by HIV/AIDS. Linkages between illness and impoverishment are critical for poverty reduction and development strategies. The HIV/AIDS epidemic is occurring particularly in populations where poverty and malnutrition is already endemic. Two main priorities highlighted by the United Nations Millennium Development Goals are eradicating extreme poverty and hunger, and combating HIV/AIDS. These two priorities are interrelated, both influencing the vulnerability to and the severity of degree to which the other is
Food insecurity is a leading cause of morbidity and mortality in sub-Saharan Africa\textsuperscript{190} and has inextricable linkages to the HIV epidemic\textsuperscript{191}. Conceptual frameworks have illustrated the increased vulnerability to HIV/AIDS that results from food insecurity and the reciprocal negative effect of food insecurity on the health of HIV-positive persons and affected households\textsuperscript{191}. Studies from Kenya and Uganda have found that the vast majority of PLWHA are moderately or severely food insecure\textsuperscript{192,193}. Furthermore, PLWHA have lower levels of social support and greater levels of internalized HIV-related stigma, which have been shown to be strong predictors of food insecurity\textsuperscript{191,194}.

At the community level, collective efficacy describes how socially cohesive and how effectively the community works together and acts as a collective whole. Due to the high HIV prevalence rate on Mfangano, this community has experienced loss of community capacity due to a decrease of productive members and increased burden of illness that deplete resources, time, and assets. There is a community awareness of the effectiveness of responding as a group. However, HIV’s divisive effects have strained how well the community responds together. Due to HIV-related stigma, PLWHA often seek support among other HIV-affected households, and may be excluded from other sources of community support. With weakened collective capacity, PLWHA, their households, and the community as a whole suffer consequences of increasing burden of illness, loss of productivity, and thus perpetuating cycles that further exacerbate the risk and vulnerability pre-disposed by Mfangano’s marginalization. Furthermore, community participants described the underlying socioeconomic inequities that the entire community confronts. Therefore, there is expressed community need for comprehensive support to overcome these disparities.

Expanding upon the consequences of HIV/AIDS for rural livelihoods in sub-Saharan Africa\textsuperscript{195}, the epidemic has diminished rural workforce capacity, agricultural productivity, and transformed the structure of rural household and communities\textsuperscript{195}. Widespread AIDS-related mortality has distorted population dynamics - decreasing the percentage of working adults and shifting the burden of household responsibilities to other members, such as to grandparents taking care of orphans\textsuperscript{196}. It has further strained the already fragile relationship between livelihoods and ecological systems, since increasing socioeconomic stressors may lead to irresponsible and unsustainable production practices to meet increasing needs\textsuperscript{195}. Rural populations are dependent on both land and labor, and the consequences of HIV have altered structures of both. HIV/AIDS kills and disables primarily adults in the most productive years of their lives\textsuperscript{189}. Studies examining the impact of HIV/AIDS on agricultural households reveal a downward spiral of livelihood degradation\textsuperscript{197,198}. Coping strategies, such as selling productive assets and reducing spending on other needs (e.g. education), can have potentially devastating long-term impacts that perpetuate the intergenerational transmission of poverty\textsuperscript{199}. Household income and resources often were diverted to meet the costs of illness\textsuperscript{199}. Labor shortages occurred since time and energy were spent to recover from illness or devoted to caretaking for those who are ill\textsuperscript{199}. Numbers of widow- and orphan-headed households have increased\textsuperscript{199}. Subsequently, there were losses of land tenure and assets following deaths of the household male since most cultures followed a patriarchal line of inheritance\textsuperscript{199}. Furthermore, the income generated by households was often consumed by health-related expenses\textsuperscript{199}. Thus, there was both decreased reinvestment back into the household and local economy\textsuperscript{200}. Additionally,
scarce and low-resourced health facilities may be unprepared to cope with the increasing burdens of HIV/AIDS related illness. This may divert limited resources away from other vital health services, such as malaria treatment and maternal/child health. Based on a cross-country review of HIV/AIDS and human development, the epidemic is no longer a crisis limited to the health care sector. It has adversely impacted, if not reversed, efforts to alleviate poverty and hunger, achieve universal primary education, promote gender equity, reduce maternal/child mortality, and ensure environmental sustainability.

Furthermore, the consequences of illness have eroded individual lives, and adversely affected families and communities as a whole. Perceived efficacy, the belief in agency, may be diminished due to changed perceptions of what can be achieved at individual, household, and community levels. Leading psychologist Bandura explains that unless people believe that they can achieve desired effects and prevent undesirable ones, they would have low incentive to act. Furthermore, if belief in agency is put towards social purposes, it fosters collective efficacy by understanding common obstacles and opportunities, fostering motivation, resilience to adversity, and commitment to shared interests. Studies show that a high sense of efficacy promotes a pro-social environment characterized by cooperativeness, helpfulness, and sharing. The communities of Mfangano have described their lived experience within an ecological framework and identified potential solutions within this framework, such as enabling encouragement at the individual level, enhancing productivity at the household level, and addressing underlying socioeconomic inequities at the community level. This elucidates the importance of comprehensive and integrated strategies to address interrelated inequities that heighten risk and perpetuate vulnerability for HIV/AIDS. Furthermore, research findings underscore the salience of collective efficacy in resource-limited areas, in which community-level support is often the most important, if not the only, resource for support.

V. Limitations

Given the small sample size in comparison to the larger Mfangano community of approximately 18,000 residents, we cannot generalize these findings beyond the studied sample. However, our exploratory study was oriented towards the development of conceptual frameworks, explanatory schemes, and useful findings for practice, and may be applicable to similar contexts and populations. This preliminary study serves as a part of initial steps to inform further research on Mfangano community health.

In regards to methodology, engaging in community-based participatory research in understanding perception of a stigmatized disease may have certain limitations. For this study, research staff were hired directly from the communities being sampled. Benefits to the research include their expertise and experience in the local and sociocultural context. Risks to the research include inadvertent disclosure, personal interpretations of community perception, and unanticipated staff influences on participant responses (such as verbal tone, facial expressions, so forth during focus group sessions).
To ensure against inadvertent disclosure, all community staff members were trained on the importance of confidentiality during the training sessions. Furthermore, staff were trained to elicit general community perceptions not individual experiences during the focus group study. To ensure against personal interpretations from staff, during the focus group process, debrief discussions were conducted afterwards with three community staff members (one moderator and two note-takers) to enhance inter-reviewer correspondence for each response reviewed, for each gender-based group. Furthermore, areas of convergence and divergence of perspectives were deliberated and documented. During the data analysis, participatory discussions were conducted with five community health workers to enhance inter-reviewer correspondence. Likewise, areas of convergence and divergence of perspectives were deliberated and documented. To ensure against unanticipated staff influences during the focus group sessions, debrief discussions allowed moderators and note-takers to provide feedback on each other’s performance during the session (such as whether the moderator was imposing her/his views on the group, whether certain questions/probes were leading questions that framed how participants responded, so forth). In summary, the research team implemented an iterative process of evaluation and improvement to minimize the risks of utilizing community-based participatory methodologies.

Furthermore, the study worked to ensure continuum in staffing throughout the multi-year, multi-phased study (quantitative, qualitative, and analysis). However, due to unforeseen life circumstances, some staff members were unavailable to participate continuously, such as moving away from Mfangano Island, taking on other employment duties, so forth. The research team worked to establish staff continuum to be best extent possible, and rehired/retrained available staff accordingly for each new phase of the multi-phased study. Furthermore, new staff were hired and trained to meet growing research needs and to ensure continuous community capacity building.

VI. Implications

Findings from this exploratory study elucidate the importance of community-level interventions to address the most salient challenges and barriers to HIV care, treatment, and support. Given the new paradigm of “treatment as prevention”, current HIV strategies advocate for testing and treating individuals as early as possible to prevent further HIV infection and transmission. Community perception can inhibit or enable individual readiness, as demonstrated by the role of stigma versus encouragement. This has crucial implications such as enabling PLWHA to access HIV-related support and enhancing collective efficacy by overcoming the divisive impacts of HIV-related stigma and discrimination. Due to Mfangano’s marginalization, communities rely mostly on community-level social support. However, consequences of HIV-related stigma/discrimination at the individual, household, and community levels have strained and weakened how the communities respond to the HIV/AIDS epidemic. Community-based interventions that address community perception of HIV/AIDS may enhance community cohesion and effectiveness in overcoming the most salient challenges and barriers faced. Furthermore, livelihood interventions that increase resources available to the community and help to diversify the access to resources may address underlying socioeconomic inequities. Comprehensive and integrated
community-level strategies would enable access to HIV care, treatment, and support, especially in resource-limited areas.

A 2011 systematic review has found that patient retention and linkage throughout the continuum of HIV care is very low\textsuperscript{203}. In sub-Saharan Africa, the median retention of people who tested positive for HIV prior to starting antiretroviral (ARV) is only 29\%. The 28 identified studies of retention showed substantial loss of individuals at every step of care, from initial CD4 count to ARV initiation. A World Health Organization survey of more than twenty countries identified key barriers and challenges at each stage of care\textsuperscript{204}, which include psychological (lack of perceived benefits, stigma, discrimination, fear, denial, lack of support), health service (poor links and referrals, poor counseling, misinformation/misconception, inefficient care, burden of illness, lack of access to health care), treatment-related (treatment fatigue, pill burden, regaining health, alternative care), among others - all which are more salient in resource limited settings. In a retrospective cohort analysis among rural health centers in Uganda\textsuperscript{205}, 81\% of patients were lost-to-follow up before ARV initiation; more than 93\% of those patients dropped out of care after their first visit to the clinic. The 19th International AIDS Conference (AIDS 2012) highlighted the importance of community-based support in improving retention in care. Adapting HIV services that are more appropriate to local context, patient-centered, decentralized, and integrated, such as enhancing community support structures and organizations, can support patient retention. According to a prospective cohort study\textsuperscript{206}, adults receiving community-based adherence support were significantly less likely to be lost-to-follow-up, and had lower mortality and improved virological suppression. Furthermore, the integration of multifaceted aspects of care and supportive services, such as food, economic, and livelihood interventions, would help to ensure comprehensiveness and continuum in addressing the interrelated socioeconomic determinants of community health\textsuperscript{207,208,209}.

\textbf{VII. Future Directions}

This exploratory study may help to shed light on how marginalization shapes perception among other vulnerable populations. Community-based participatory approaches to research involve communities as equal partners to understand the social construction of their perceptions as well as to identify potential solutions that address their most salient needs. Communities of Mfangano have witnessed the detrimental effects of HIV at the individual, household, and communities levels, while also expressing what they perceive would be helpful in overcoming challenges and barriers faced, such as receiving encouragement, enhancing productivity, and addressing underlying socioeconomic inequities. Communities have described their lived experience within an ecological framework and how they respond through social capital.

Lastly and as importantly, the baseline community health research, in which this qualitative study served as one part, has identified many associations with HIV as perceived by the Mfangano community. This information will help community providers, such as the Organic Health Response-Ekialo Kiona Center, and Family AIDS Care and Education Services, to strengthen programs to address the multifaceted and interrelated socioeconomic impacts resulting from the HIV/AIDS epidemic.
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Focus Group Guide for Social Support

I. INTRODUCTION

My name is ___________________. I am working with the Kenya Medical Research Institute, the University of California in the United States, and the Ekialo Kiona Center on a project aiming to understand the issues faced on Mfangano. With me today are (note-taker’s names). We would like to talk to you about things that affect your community, including the support that community members receive, the types of support and when it’s received, and how HIV/AIDS and jaboya are related to support. In the long-term, the information that you provide will be used to inform efforts to strengthen and improve programs on Mfangano.

We would like to hear about your general experiences and opinions about how things happen in your community, we do not want information about specific persons or personal situations. There are no right or wrong answers to the questions I will be asking and you are free not to answer any questions that you don’t want to. We hope that everyone will feel free to express his/her thoughts.

Today’s discussion is confidential. We will not link what you say back to you and when we write about this discussion we will not use any names. Please also do not discuss what you hear in this room once you leave.

This discussion will not take too much time (up to two hours). If you have questions you want to ask on other topics, we can assist you to find answers after the group discussion is over.

To help me with the analysis, I would like to ask your permission to take written notes of what is said and to make a digital recording of the conversation. Are you willing to participate in our discussion? Do we have your permission to record the discussion?

Next, we would like to ask your consent to participate in the discussion. (Summarize the consent form and have each person who is willing to participate sign the form)

Before we begin, we have some group norms that we would like everyone to agree to. (Introduce group norms for the discussion)

(Start the tape recorder AFTER the introductions part of the discussion. This guide includes the topics to be covered and questions that may be helpful in facilitating the discussion. You do NOT have to ask all the questions or follow the order given in the guide. Major topic areas and questions are indicated in Bold.)
First let’s get acquainted. Let’s go around the circle and each person can introduce herself/himself. You can tell us your first name, how many children you have, and anything else about yourself that you would like to tell the group. (Members of the research team should also introduce themselves. If the group agreed to the tape recording, you may start recording after this section of the discussion.)

III. DISCUSSION TOPICS

Today, we are going to talk about some of the following topics: types of social support, seeking support, food and support, jaboya and support, health/HIV and support, and wealth and support.

A. Types of Social Support
   a. Let’s start out by talking about what support means in this community. What things are considered supportive in this community? (Emotional, governmental, social, occupational, etc.) – Luo version: From where do you get your support?
   b. What types of support are most important for your community to be healthy? Public support (government, NGO)? from family members? from friends?
   c. Are there types of support that are lacking in your community?
      i. What are they?
      ii. Why do you think they are lacking?
   d. In your community, are there people who receive a lot of support? What groups of people?
   e. Are there people who receive very little support? What groups of people?

B. Seeking Support
   a. In your community, can it be difficult to ask for support? Or is it always offered?
      i. Is it more challenging to ask for material support (like money or food) than non-material support (like childcare, someone to talk to, someone to keep secrets)?
      ii. Is it more difficult for some types of people to ask for support than others? Who would have more difficulty seeking support?
      iii. Is it easier for men or women to ask for support?
         1. Are men more comfortable asking for material or non-material support?
         2. Are women more comfortable asking for material or non-material support?
         3. Are men or women more likely to receive support?

C. Food and Support
   a. Now we’ll talk a bit about specific forms of support. First, we’d like to talk about sharing of food. In your community, when do people share food?
   b. What types of food do people share? Are there types of food that are not shared?
c. In your community, do people often share food or cooked meals with others?
   i. Does a household share food with many other households, or just a few?
   ii. Who do people share with? Families, friends, strangers?
d. Do people ask for support with the sharing of food if they do not have enough food?
   i. Do people share food with people who ask?
   ii. Do people share food with people that they believe need food?

D. Jaboya and Support
a. Continuing with a topic related to food, we want to discuss a sensitive topic. As a reminder, we don’t want to talk about specific people. In this community, can you describe the practice of jaboya?
b. Why do people practice jaboya in your community?
c. Do people use jaboya as a way to get food, or to get money, or other things?
d. What types of women practice jaboya in your community?
   i. Are the women who practice jaboya from the following groups:
      1. Mother
      2. Young girl
      3. Old woman
      4. Widow
      5. Poor
      6. Rich
   ii. Are they from the island? Or also members of communities off the island?
   iii. Do they drink alcohol or spirits (or cigarettes or mind altering substance/drugs)?
e. What types of men practice jaboya in your community?
   i. Are the men who practice jaboya from the following groups:
      1. Fathers
      2. Young men
      3. Old men
      4. Fishermen
      5. Farmers
      6. Poor
      7. Rich
      8. Polygamous
      9. Single
f. In what type of household would you expect to see jaboya?
   i. Poor family
   ii. HIV-affected family
   iii. Widowed family
   iv. Fishing family
   v. Others?
g. Do people who practice jaboya have a lot of support from family and friends or a little support from family and friends?
h. How does jaboya relate to having enough food?

E. Health, HIV, and Support
   a. Now we’ll talk a bit about another specific form of support -- we’d like to talk about how health relates to support.
   b. In your community, do people ask for support if they’re facing health problems?
      i. What kinds of health problems do people ask for support with?
      ii. Are there certain problems for which it is more difficult to ask for support?
   c. If someone has HIV are they more or less likely to get support?
   d. If children have HIV, is more social support offered than for adults with HIV?
   e. Does a household where someone has HIV have more or less support?
      i. Do you think this impacts whether someone discloses their HIV status to the community?
   f. How do illness and HIV influence social support in your whole community?

F. Wealth and Support
   a. In your community, what is the relationship between wealth (having money) and social support?
   b. In your community, do poor families or wealthy families have more social support?
      i. Is social support more important for poor households or wealthy households?
      ii. Is it easier for poor households or wealthy households to request support?
      iii. Is it easier for poor households or wealthy households to receive support?
   c. How does your social network – the people that you know, through family, school, friendships, work, sports, etc – impact how you receive support?
      i. Does having a large social network help or prevent a family from becoming wealthy?
      ii. Does having a large family and extended family help or prevent a family from becoming wealthy?
   d. Do people with lots of social support obtain more material items through their network? Do people with lots of social support obtain more non-material items through their network?

G. Expectations of Support
   a. Now let’s talk about the kind of people that provide support, and who is expected to give different types of support. In your community, what kind of people and groups provide support for people that need it?
   b. In your community, do people expect support from certain people or groups?
   c. Do expectations differ for different groups?
i. Do friends and relatives provide the same types of support?
ii. Who do people usually turn to for support in the following areas?
   1. Help with school fees
   2. Help with medical fees
   3. Labor, like to build a house
   4. Sharing food
   5. Someone to talk to
   6. Emotional support or affection
   7. Help with child care
   8. Help with doctor’s visits
   9. Someone to share secrets with

H. Suggestions for providing more support
   a. What could be done to increase support in this community?

IV. CLOSING

Thank you very much for your time. Your responses will be very helpful for improving health services for Kenyan families. If you have any questions about the topic that we discussed today, feel free to speak with our Ekialo Kiona VCT counselors right after this discussion. They will be able to answer your questions or refer you to outside resources.

(Record participant characteristics on form if have not finished.) (Correct any important misconceptions and provide referrals to VCT, PMTCT, or ARV services, if appropriate.)
Appendix: A.b

I. TIMO NG’ERUOK.
Nyinga en_________________. Atiyo gi jo Kenya Medical Research Institute, mbalariany mar California San Francisco manie United States, Kod Ekialo Kiona Center e chenro madwaro ng’eyo gik matimore e Chula mar Mfangano. Ka wan kod (Nyinge jandiko). Dwaher mar wuoyo kodu kuom gik matimore e gweng’, moriwore gi kony ma jogweng’ yudo, kit kony, kod kinde ma iyudogie, kendo kaka tuo mar kute mag ayaki kod jaboya otudore gi kony. Gikone, weche ma uchiwo ibiro tigo kuom nyiso gik mosetim mondo otiog’ogur kendo oting’ malo/omed chenro mag dongruok ei Mfangano.

Dwaher ma r wuoyo kodu kuom gik matimore e gweng’. Ok wadwar wach mawuoyo kuom ng’ato ang’ata kata wach momaki in iwuon. Onge duoko marach kata maber ne penjo mabiro penjo, kendo bende in thuolo mar weyo mokiduoko gima ineno ni ok inyal duoko. Wan gi geno ni ng’at ang’ata ni thuolo mar golo pache.

Twak ma kawuononi gin weche maling’ling’. Ok wabitudi gi wach moro amora miwacho kendo ka wandiko wach kuom maling’ling’ ok wabitiyo gi nying ng’ato ang’ata. Wakwayi ni kik iwach wechegi kiwuok oko mar odni. Wachni/Twagni ok bikawo thuolo malach (kinde madirom seche ariyo). Ka in gi penjo e wi wachno kata e wechego wanyalo konyi yudo duoko bang’ tieko twagni kanyakla. Mondo ukonya e winjo twakni, daher mar kwayo thuolo mar ndiko kendo kawo wechegi kod masindni. Bende un thuolo mar twak? Bende wan gi thuolo mar mako wecheu gi masindni?

Maluwo mano, dwakwau ni mondo uyie bedo e twagni. (Pong’ kalatasni kendo ng’ato ka ng’ato moyie bedo e twak mondo oket sei). Kapok wachako, nitie/wan gi chike moko mag kanyakla. (Yangi chike mag twak mar kanyakla).

(Yaw masindni bang’ timo ng’eruok e twak). Okang’ni oriwo thuond weche maibiro wuoye kendo penjo manyalo konyo e twagni. Ok ochuno ni nyaka ipenj penjo te kata ilugi kaka gi no. Thuond weche kod penjo onyis e ndiko modhienyore.

II. TIMO NG’ERUOK.

III. THUOND WECHE MAG TWAK.
Kawuono wadhi wuoyo kuom thuond wechegi: Kit kony miyudo kanyakla, Kaka inyalo kwa/manyo kony, chiemo kod Kony, Jaboya Kod Kony, Ngima/Kute mag Ayaki kod Kony, gi Mwandu kod Kony.

A. Kit Kony Mar Kanyakla.

a) Mokwongo wachak kwawuoyo kuom tiend kony ei gweng’. Ang’o gini mineno kaka konyruok ei gweng’ni?

b) En kit kony mage maber ahinya moloyo e gweng’u ka mondo ubed gi ngima maber? Kony moa kuom sirikal, koso riwruoge mag NGO? Moa kuom anyuola? Moa kuom osiepe?

c) Bende nitie kony ma onge e gweng’ni?

   i. Gin mage?
   
   ii. Ang’o momiyo uparo ni gi onge?

d) E gweng’ni, bende nitie jok mayudo kony? Grube kata kanyakla mage?

e) To bende nitie jok mayudo kony matin ahinya? Grube kata Kanyakla mage?

B. Dwaro/Manyo Kony.

a) E gweng’uni, bende nyalo bedo matek kwayo kony koso? Koso en gima iyudo ayuda seche duto?

   i. Bende en gima tek kwayo kony mar pesa kata chiemo moloyo kony mar rito nyathi, wuoyo gi ng’ato, kod ng’ato manyalo kano wecheni maling’ling’.

   ii. Bende en gima tek ne jomamoko kwayo kony moloyo jomamoko? Ng’ano manyalo bedo gi pek mang’eny e kwayo kon y?

   iii. En gima yot ne jomachwo koso ne jomamine kwayo kony?

      1. Bende jomachwo yudo yot kuom kwayo chiemo kata pesa koso kony mar rito nyithindo, kony mar ng’ato ma iwuoyo godo, kata ng’ato ma kano wecheni maling’ling’?

      2. Bende jomamine yudo yot kuom kwayo chiemo kata pesa koso kony mar rito nyithindo, kony mar ng’ato ma iwuoyo godo, kata ng’ato ma kano wecheni maling’ling’?

      3. Ekind jomachwo gi jomamine ere jomanyalo yudo kony e yo mayot?

C. Chiemo Kod Kony.

a) Sani wabiro wuoyo matin kuom kony mopogore opogore. Mokwongo, dwaher mar wuoyo kuom pogo chiemo. E gweng’u ka, e seche kata ndalo mage ma ji pogo e chiemo?
b) Kit chiemo mage ma ji pogo kata chamo kanyakla? Bende nitie kit chiemo moko mokipogi kata riw kamoro achiel?

c) E gweng’u ka, bende ji pogore chiemo kata chiemo kanyakla koso chiemo motedi kanyakla gi jomoko?
   i. Bende joot machielo pogo chiemo ne joute mang’eny mamoko, koso mana matin?
   ii. Ng’ano ma ji pogo godo chiemo? Joot, osiepe, kata joma ok ong’ere?

d) Bende ji kwayo kony mar pogo chiemo kadipo ni gionge chiemo moromo?
   i. Bende ji pogo chiemo ne jomamoko mokwayogi?
   ii. Bende ji pogo chiemo gi joma ging’eyo ni dwaro chiemo?

D. Jaboya Kod Kony.

a) Kawadhi nyime gi thuon wach moriwore kod chiemo, wadwaro wuoyo kuom weche maiye. Kwaparonu, ok wadwar wuoyo kuom ng’ato ang’ata. É gweng’ni, bende unyalo nysiswa/lerowa gima jaboya timo?

b) Ang’o momiyo ji bedo jaboya kata bedo gi jaboya e gweng’u?

c) Bende ji tiyo gi joboya kaka yor yudo chiemo, koso pesa, koso gik mamoko?

d) Gin kit mine mage manigi jaboya e gweng’ni?
   i. Bende jomamon manigi jaboya wuok e riwrugo/grube ma piny gi?
      1. Miyo.
      2. Nyako.
      3. Miyo mo ti (Miyo maduong’).
      4. Chi liel.
      5. Jachan (Miyo).
   ii. Bende gin jo Mfangano? Koso joma wuok e gwenge mamoko oko mar Mfangano?
   iii. Bende gimadho kong’o (bia koso chang’aa).

e) Gin chwo machal nade ma joboya e gweng’?
   i. Bende nitie chow ma gin joboya koa kuom grube/riwrugegi?
1. Wuone.
2. Chwo matindo.
3. Chwo madongo.
4. Chwo majolupo.
5. Jopur.
6. Chwo ma jochan.
7. Chwo ma jomwandu.
9. Chwo ma pok okendo.

f) E ute/mier machal nade miyude jaboya?
   i. Ute jochan.
   ii. Mier/ute ma jomoko kuomgi nig i kute mag ayaki.
   iii. Mier maonge wegi machwo.
   iv. Mier jolupo.
   v. Mamoko?

g) Bende joma nie achiel gi ja boya yudo kony mang’eny koa kuom joot/anyuola kod osiepe koso giyudó kony matin koa kuom anyuolagi kod osiepe?

h) Ere kaka jaboya otudore gi bedo gi chiemo mang’eny moromo?

E. Ngima, Kute mag Ayaki kod Kony.

a) Sani wabiro wuoyo kuom kit kony moro-dwaher mar wuoyo kuom kaka ngima otudore gi kony.

b) E gweng’u ka, bende ji kwayo kony ka gin gi chandruok e ngimagi?
   i. Gin chandruok mage ma ka ji ni godo to gi kwayo kony?
   ii. Bende nitie chandruok moko ma ok yot kwayo negi kony?

c) Kadipo ni ng’at machielo ni gi kute mag ayaki bende gin gi thuolo mang’eny koso matin mar yudo kony?

d) Kadipo ni nyithindo e manigi kute mag ayaki, bende giyudo kony mar kanyakla mang’eny moloyo ka jomadongo e manigi kute mag ayaki?

e) Bende ot ma ng’ato ni kute mag ayaki yudo kony mang’eny koso matin?
i. Bende iparo ni ma kelo kanyakla ka ng’ato ofulo chalne kuom kute mag ayaki e gweng’?

f) Ere kaka touché kod kute mag ayaki jiwo kony mar kanyakla e gweng’ mangima?

F. Mwandu Kod Kony.

a) E Gweng’u, en tudruok mane manitie ekind mwandu (bedo kod pesa) gi kony mar kanyakla?

b) E gweng’u, bende jochan koso jomwandu manigi konyruok mang’eny mar kanyakla?
   i. Bende kony mar kanyakla ber moloyo ne jochan koso jomwandu?
   ii. Bende en gima yot ne jochan koso ne jomwandu kwayo kony?
   iii. Bende en gima yot ne jochan koso ne jomwandu yudo kony?

c) Ere kaka ng’eruok mari kaluwore gi-joma ing’eyo, kuom anyuola kata wede, e skul, osiep, tich, tuke mag sport, gimamoko- ni gi teko kuom yudo kony?
   i. Bende bedo gi tudruok/ng’eruok malach miyo joot yudo koso geng’ogi kuom bedo gi mwandu?
   ii. Bende bedo gi joot mang’eny gi anyuola konyo koso geng’o joot bedo gi mwandu?

d) Bende jomanigi kony ma kanyakla mang’eny yudo pesa kata chiemo mang’eny? E yor tudruok? Bende jomanigi kony ma kanyakla mang’eny yudo kony mar rito nyithindo, joma ginyalo wuoyo godo kata joma nyalu kano wechegi maling’ling’.

G. Konyruok Migeno.

a) Koro wawuo kuom jogo machiwo kony, kendo ma igeno ni biro chiwo kony mopogore opogore. E gweng’uni, gin jok mage kata riwrugo gi machiwo kony ne jogo man gi dwaro?

b) E gweng’u ka, bende ji geno yudo kon koa kuom jomamoko koso kanyakla/grube?

c) Bende geno/dwaro opogore kaluwore gi riwrugo?
   i. Bende osiepe kod wede chiwo kony machalre?
   ii. En ng’a ma ji ng’iyo mondo omigi kony kuom gik mondik pinyka.
      1. Kony mar pesa mag skul.
      2. Kony mar pesa mag thieth.
4. Pogo chiemo.
5. Ng’ato miwuoyo go.
8. Kony mar limbe mar thieth.
9. Ng’ato ma inyalo wachone wecheni maling’ling’ kata mopondo.

H. Pachu Kata Dwachu Kuom Chiwo Kony Mang’eny.
a) En ang’o monengo tim mondo ojìw kony e gweng’ri?

IV. LORO.
Erokamano uru ahinya kuom thuolou. Duoko meku biro konyo ahinya e tingruok malo tije mag thieth ne Jokenya. Kadipo ni un gi penjo kuom thuond weche mwawuoye kawuono beduru thuolo mar wuoyo kod Johocho mag Ekialo Kiona bang’ ma eri. Gibiro miyou duoko mag penjogo kata gibiro siemonu kamoro oko munyalo yudogie. (Record Participant characteristics on form if have not finished). Tem ng’eyo winjo madibede marach kendo chiw ne jo VCT, PMTCT, kata ARV services, kaka nyalore.
Appendix: B.b

Focus Group Guide for Food, Income, Environment

I. INTRODUCTION

My name is ______________. I am working with the Kenya Medical Research Institute, the University of California, San Francisco in the United States, and the Ekialo Kiona Center on a project aiming to improve understanding of issues faced on Mfangano. With me today are (note-taker’s names). We would like to talk to you about things that affect your community, including how people earn money, the ways people use the environment, the availability of food in the community, and jaboya. In the long-term, the information that you provide will be used to inform efforts to strengthen and improve programs on Mfangano.

We would like to hear about your general experiences and opinions about how things happen in your community, we do not want information about specific persons or personal situations. There are no right or wrong answers to the questions I will be asking and you are free not to answer any questions that you don’t want to. We hope that everyone will feel free to express his/her thoughts.

Today’s discussion is confidential. We will not link what you say back to you and when we write about this discussion we will not use any names. Please also do not discuss what you hear in this room once you leave.

This discussion will not take too much time (up to two hours). If you have questions you want to ask on other topics, we can assist you to find answers after the group discussion is over.

To help me with the analysis, I would like to ask your permission to take written notes of what is said and to make a digital recording of the conversation. Are you willing to participate in our discussion? Do we have your permission to record the discussion?

Next, we would like to ask your consent to participate in the discussion. (Summarize the consent form and have each person who is willing to participate sign the form)

Before we begin, we have some group norms that we would like everyone to agree to. (Introduce group norms for the discussion)

(Start the tape recorder AFTER the introductions part of the discussion. This guide includes the topics to be covered and questions that may be helpful in facilitating the discussion. You do NOT have to ask all the questions or follow the order given in the guide. Major topic areas and questions are indicated in Bold.)
II. INTRODUCTIONS

First let’s get acquainted. Let’s go around the circle and each person can introduce herself. You can tell us your first name, how many children you have, and anything else about yourself that you would like to tell the group. (Members of the research team should also introduce themselves. If the group agreed to the tape recording, you may start recording after this section of the discussion.)

III. DISCUSSION TOPICS

A. Livelihoods and Income
   a. In your community, what are the main ways that people support themselves? By this, we mean the ways people get food, money, and other means to survive.
      i. What types of support are most successful (easiest)? Least successful (most difficult)?
      ii. Is it important that a household has many different sources of income?
      iii. How is education related to a household’s ability to support itself?
          1. Are there other factors that affect a household’s ability to support itself?
          2. Does your social network – the people you know and your family – affect your income in a positive and negative way?
   b. In your community, do men and women do different jobs to earn money? Do they do different jobs to provide food for their families?
      i. What jobs do men do to earn money?
      ii. What jobs do men do to provide food for their families?
      iii. Are they the same?
      iv. What jobs do women do to earn money?
      v. What jobs do women do to provide food for their families?
      vi. Are they the same?
   c. In your community, do households have enough money to live on?
      i. What things do people struggle to pay for?

B. Food Security
   a. In your community, do people have enough food?
      i. Are there times of the year when some people are lacking food?
      ii. Are there some groups of people who are lacking food? Which groups?
   b. In your community, how does your job affect your household’s ability to get enough food?
      i. How does a household’s ability to get food relate to the following:
          1. Having enough money to buy food
          2. Having household members who are fishermen
          3. Having a productive farm or a big farm
      ii. What times of year are most difficult to feed your family? Why?
      iii. What times of year are least difficult to feed your family? Why?
   c. Do any other factors affect a household’s ability to have enough food?
d. Over time, has households’ ability to get enough food changed in your community? Is it harder or easier to get enough food compared to the past?
   i. Have there been changes to where food comes from? Does the same amount come from fishing and from farms as compared to the past?
   ii. What do you think has caused these changes?

e. Thinking about the different kinds of foods people eat in your community, are there certain types of foods that people most worry about not having enough of?
   i. If there’s not enough food, who in the house has the most priority (who eats first) to receive food? Who has the least priority (who eats last)?

f. What types of foods do people need to eat to keep them healthy?

g. Are food and illness related in your community?

h. Do foods ever serve as medicines?
   i. Does the lack of food make taking medicine more difficult?

C. Fishing

  a. Now we would like to talk more about specific activities that both earn money and provide food. First, lets talk about fishing. How do you view fishing in this community?

  b. In your community, are there times when there are not enough fish? What is the effect (negative)?
   i. Are people concerned about the lake lacking fish?
   ii. What causes there to be not enough fish?
   iii. How do the fishing rules (net size, hole size in the net, minimum fish size, etc) affect the community’s ability to get enough fish?

  c. How does fishing affect health in your community?

D. Farming

  a. In your community, is having a farm related to your ability to have enough food?
   i. Is having enough food related to the following:
      1. the size of your farm
      2. the crops you grow
      3. the techniques you use on the farm

  b. In your community, has farming had an effect on the environment of Mfangano?
   i. Are you concerned about these changes to the environment?
   ii. In your community, if a household doesn’t have enough food, does that impact the way they farm?
   iii. If a household has a member who is sick, does that impact the way they farm?

  c. How does farming affect health in your community?

E. Management.

  a. In your community, how do people manage their income/salary?
  b. How do people manage their food?
   i. Such as leftovers.
  c. Do people save their money? If so, how?

F. Jaboya, Food, and Environment.
a. Continuing with our topic related to food, we want to discuss a sensitive subject. As a reminder, we don’t want to talk about specific people. In this community, can you describe the practice of jaboya?
b. What types of women practice jaboya in your community?
   i. Are the women who practice jaboya from the following groups:
      1. Mother
      2. Young girl
      3. Old woman
      4. Widow
      5. Poor woman
      6. Rich woman
   ii. Are they from the island? Or also members of communities off the island?
c. What types of men practice jaboya in your community?
   i. Are the men who practice jaboya from the following groups:
      1. Fathers
      2. Young men
      3. Old men
      4. Fishermen
      5. Farmers
      6. Poor man
      7. Rich man
      8. Polygamous
      9. Single men:
         a. Widower
         b. Bachelors
d. Do people use jaboya as a way to get food or money? In what type of household would you expect to see jaboya?
   i. Poor family
   ii. HIV-affected family
   iii. Widowed family
   iv. Fishing family
   v. Others?
e. In your community, do women who practice jaboya have enough food?
f. In your community, do women who practice jaboya have access to food from fishing or farming?

G. Water treatment
   a. We would like to ask a few more questions about another issue related to the environment – water. Is there a need for safe drinking water? Are there problems getting safe drinking water?
   b. Do you think people who use chemicals (water guard) to treat water use them every time?
   c. What do you think the consequences are to not treating your water?

H. Solutions
   a. Today we have discussed many topics related to the environment – including livelihoods, food, fishing, farming, jaboya, and water. Do you see any solutions that the community could undertake to address these issues?
i. Having enough food
ii. Fishing
iii. Farming
iv. Jaboya
v. Water Treatment

IV. CLOSING

Thank you very much for your time. Your responses will be very helpful for better understanding the experiences of people on Mfangano (Record participant characteristics on form.) (Correct any important misconceptions and provide referrals to services, if appropriate.)
Appendix: B.b

I. TIMO NG’ERUOK.
Nyinga en_________________. Atiyo gi Kenya Medical Research Institute, mbalariany ma California San Francisco United States, Kod Ekialo Kiona Center e chenro madwaro jiwo ng’eyo gik matimore e Chula mar Mfangano. Ka wan kod (Nyinge jandiko).
Dwaher mar wuoyo kodu kuom gik matimore e gweng’, moriwore gi kaka ji yudo pesa, kaka ji tiyo gi aluöra, bedo mar chimeo e gweng’ kendo jaboya. Gikone gik ma ubiro wacho biro jiwo kendo ting’o malo chenro mag dongruok e Mfangano.

Dwaher mar winjo gik ma useneno/winjo gi paro ma un go kuom gik matimore e gweng’. Ok wadwar wach mawuoyo kuom ng’ato ang’ata kata wach momaki in iwuon. Onge duoko marach kata maber ne penjo mabiro penjo, kendo bende in thuolo mar weyo mokiduoko gima ineno ni ok inyal duoko. Wan gi geno ni ng’at ang’ata ni thuolo mar golo pache.

Twak ma kawuononi gin weche maling’ling’. Ok wabitude gi wach moro amora miwacho kendo ka wandiko wach kuom maling’ling’ ok wabitiyo gi nying ng’ato ang’ata. Wakwayi ni kik iwach wechegi kiwuok oko mar odni.
Wachni/Twagni ok bikawo thuolo malach (kinde madirom seche ariyo). Ka in gi penjo e wi wachno kata e wechego wanyalo konyi yudo duoko bang’ tieko twagni kanyakla. Mondo ukonya e winjo twakni, daher mar kwayo thuolo mar ndiko kendo kawo wechegi kod masindni. Bende un thuolo mar twak? Bende wan gi thuolo mar mako wecheu gi masindni?

Maluwo mano, dwakwau ni mondo uyie bedo e twagni. (Pong’ kalatasni kendo ng’ato ka ng’ato moyie bedo e twak mondo oket sei).
Kapok wachako, nitie/wan gi chike moko mag kanyakla. (Yangi chike mag twak mar kanyakla).

(Yaw masindni bang’ timo ng’eruok e twak). Okang’ni oriwo thuond weche maibiro wuoye kendo penjo manyalo konyo e twagni. Ok ochuno ni nyaka ipenj penjo te kata ilugi kaka gin no. Thuond weche kod penjo onyis e ndiko modhienyore.

II. TIMO NG’ERUOK.

III. THUOND WECHE MAG TWAK.
A. Yor Dak kod Yuto.
   a. E gweng’u, ere yore madongo ma ji yuto godo?
      Ma oulo ni yore ma ji yudo go chimeo, pesa, kod yore mamoko mag dak.
      i. Ere kit kony mayudore e yo mayot moloyo? Mayudo tek moloyo?
ii. Bende en gimakare ni mondo joot obed gi yore mangeny mag yuto?

iii. Ere kaka somo otudore kod nyalo mar joot e konyruok giwege?
   1. Bende nitiere gik moko mamiyo joot bedo gi nyalo mar yudo konyruok kendgi?
   2. Bende tudruok/ng’eruok mari kaluwore-gi jok ming’e yo kod joodi keloni pek yot eyote ni mag yuto?

b. E gweng’u, bende jomachwo kod jomamine tiyo tije mopogore mondo giyud pesa? Bende gitimo tije mopogore opogore mondo giyud chiemo ne joutegi?
   i. Tije mage ma jomachwo timo mondo giyud pesa?
   ii. Gin tije mage ma jomachwo timo mondo giyud chiemo ne joutegi?
   iii. Bende gichal?
   iv. Tije mage ma jomamine timo mondo giyud pesa?
   v. Tije mage ma jomamine timo mondo giyud chiemo ne joutegi?
   vi. Bende gichal?

c. E gweng’u, bende joot nigi pesa moromo dagogi?
   i. Gin gik mage ma ji nigo gi pek e yor chudo?

B. Rapim/Kar rom Chiemo.
   a. E gweng’u, bende ji nigi chiemo moromo?
      i. Bende nitie kinde moko e higa ma jomoko bedo maonge gi chiemo?
      ii. Bende nitie ji makoso chiemo?
   b. E gweng’u, ere kaka tiji nigi nyalo e odi mar bedo gi chiemo moromo?
      i. Ere kaka bedo gi teko/nyalo kuom joot e yudo chiemo otudore gi magi:
         1. Bedo gi pesa moromo ng’iewo chiemo.
         2. Bedo gi joot ma jolupo.
         3. Bedo gi puodho machwe kata maduong’.
      ii. En kinde mage e higa matek ahinya miyo joute magu chiemo?
         Nang’o/Nikech ang’o?
      iii. En kinde mage e higa mayot moloyo miyo joute magu chiemo?
         Nang’o/Nikech ang’o?
   c. Bende nitie gimachielo/yomachielo mamiyo joot yot kata pek mar yudo chiemo moromo?
   d. E kinde malach bende, yor yudo chiemo moromo kuom joot osebedo gi lokruok e gweng’u? Bende tek koso yat yudo chiemo moromo ekindegi moloyo odichienge mokalo?
      i. Bende pogruok osebetie kaluwore gi kama chiemo yae? Bende rech kata cham pod yudore maber kaka chon?
      ii. Iparo ni ang’o mosekelo pogruogegi?
   e. Kiparo pogruok/ tieng’ mang’eny mag chiemo ma ji chamo e gweng’u, bende nitie kit chiemo moko ma ji parore kuomgi ni ok giyudre moromo?
i. Kadipo ni onge chiemo moromo, en ng’a e ot man gi thuolo mar kwongo yudo chiemo? Ng’a ma kawo thuolo mogik e yudo chiemo?

f. Kit chiemo mage ma ji onegocham mondo omi gibed gi ngima maber?

C. Lupo.

a) Sani dwaher mar wuoyo mang’eny kuom kit tije mitimo ma kelo yuto mar pesa kod chiemo. Mokwongo, wawuo e lupo. Inenonade lupo e gweng’u?

b) E gweng’u, bende nitie kinde ma onge rech moromo? Gin pek kata yot mage miyudo e kindego?

i. Bende ji nigi parruok kuom bedo maonge rech e nam?

ii. Ang’o gini mamiyo rech ok bedie moromo?

iii. Ere kaka chike mag lupo (lach mar tol, rech mathindo (undersize), gimamoko) nigi tudruok e nyal mar yudo rech e gweng’ ka?

c) Ere kaka lupo kelo lokruok e ngimaji /health e gweng’?

D. Pur.

a) E gweng’u ka, bende bedo gi puodho otudore gi nyal mar bedo gi chiemo moromo?

i. Bende bedo gi chiemo moromo otudore gi magi:

1. Kar rom puodho.

2. Kit cham mupuro.

3. Kit yore mag pur me puothewa.

b) E gweng’u, bende nitie gima pur osetimo e aluora mar Mfangano?

i. Bende in gi parruok kuom lokruogegi mosetimore e aluorani?

ii. E gweng’u, kadipo ni joot onge gi chiemo moromo bende mano ni gi gima otimo e yor gi mar pur?

iii. Kadipo ni joot nigi ng’a ma tuo, bende mano nigi tudruok e yor gi mar pur?

c) Ere kaka pur otudore gi ngimaj /health ji e gweng’?

E. Yor Tiyo Gi Gigeni kaka Chiemo Kod Pesa.

a) Ere kaka jitiyo gi yutogi /pesagi mag msara e gwengu ka?

b) Ere kaka utiyo gi chembu?

i. Machalo kaka chiemo modong’ kata monindo.

c) Bende ukano pesau? Ka uyie, ere kaka ukeno?

F. Jaboya, Chiemo Kod Aluora.
a) Kwadhi nyime gi thuond wach motudore gi chiemo wadwaro wuoyo kuom wach maiye. Kar paronu, ok wadwar wuoyo kuom ng’ato ang’ata. E gweng’ni bende unyalo nyisowa gima jaboya timo?

b) Gin kit mine mage manigi jaboya e gweng’ni?
   iv. Bende jomamon manigi jaboya wuok e riwruoge/grube ma piny gi?
     7. Miyo.
     8. Nyako.
     9. Miyo mo ti (Miyo maduong’).
     10. Chi liel.
     11. Miyo ma Jachan.
     12. Miyo ma Jamwandu.
   v. Bende gin jo Mfangano? Koso joma wuok e gwenge mamoko oko mar Mfangano?

c) Gin chwo machal nade ma joboya e gweng’?
   ii. Bende nitie chwo ma gin joboya koa kuom grube/riwruogegegi?
     10. Wuone.
     11. Chwo matindo.
     13. Chwo majolupo.
     15. Chwo ma jochan.
     17. Jodoo.
     18. Chwo maonge e kend.
     a. Chwo ma monde gi otho/Chwo liete.
b. Wuoyi mapok okendo/misumba.

d) Bende ji tiyo gi joboya e yor yudo chiemo koso pesa? E ute/mier machal nade miyude jaboya?
   vi. Ute jochan.
   vii. Mier/ute ma jomoko kuomgi nigig kute mag ayaki.
   viii. Mier maonge wegi machwo.
   ix. Mier jolupo.
   x. Mamoko?

e) E gweng’u, bende jomamine manigi joboya nigig chiemo moromo?

f) E gweng’u, bende jomamine manigi joboya yudo thuolo mar yudo chiemo eyor lupo kata puro?

G. Thiedho Pii.

a) Dwaher mar penjou penjo moko kuom wach moro motudore gi aluora-Pii. Bende nitie dwaro mar pii maler mar modho e gweng’u/ bende nitie chandruok mar yudo pii maler mar modho e gweng’u?

b) Bende iparo ni joma tiyo gi yath (water guard) e thiedho pii tiyo kodgi e seche duto kapok gi tiyo gi pigno?

c) Ang’o miparo ni nyalor timore e bedo ni ok ithiedho pii mar modho?

H. Duoko.

Kawuono wasewuoyo kuom thuond weche mang’eny motudore gi aluora-Yor dak, chiemo, lupo, pur, jaboya, kod pii. Bende ineno ni nitie gima jogweng’ nyalor timo kaluwore gi loso wach mar?
   ii. Bedo gi chiemo moromo.
   iii. Lupo.
   iv. Puro.
   v. Jaboya.
   vi. Thiedho pii.

IV. LORO.

Erokamano uru ahinya kuom thuolou. Duoko meku biro konyo ahinya e tingruok malo tije mag thieth ne Jokenya. (Record Participant characteristics on form). Tem ng’eyo winjo madibede marach kendo chiw ne jo VCT, PMTCT, kata ARV services, kaka nyalore.
Appendix: C.a

Focus Group Guide for HIV/AIDS Attitudes and Behavior

I. INTRODUCTION

My name is _________________. I am working with the Kenya Medical Research Institute, the University of California, San Francisco in the United States, and the Ekialo Kiona Center on a project aiming to improve understanding of issues faced on Mfangano. With me today are (note-taker’s names). We would like to talk to you about things that affect your community, including the general knowledge of community members about HIV/AIDS, how people in the community perceive the disease, the attitudes/behaviors/beliefs of community members about it, as well as thoughts and feedbacks on existing HIV/AIDS treatment programs and information sources. In the long-term, the information that you provide will be used to inform efforts to strengthen and improve programs on Mfangano.

We would like to hear about your general experiences and opinions about how things happen in your community, we do not want information about specific persons or personal situations. There are no right or wrong answers to the questions I will be asking and you are free not to answer any questions that you don’t want to. We hope that everyone will feel free to express his/her thoughts.

Today’s discussion is confidential. We will not link what you say back to you and when we write about this discussion we will not use any names. Please also do not discuss what you hear in this room once you leave.

This discussion will not take too much time (up to two hours). If you have questions you want to ask on other topics, we can assist you to find answers after the group discussion is over.

To help me with the analysis, I would like to ask your permission to take written notes of what is said and to make a digital recording of the conversation. Are you willing to participate in our discussion? Do we have your permission to record the discussion?

Next, we would like to ask your consent to participate in the discussion. (Summarize the consent form and have each person who is willing to participate sign the form)

Before we begin, we have some group norms that we would like everyone to agree to. (Introduce group norms for the discussion)

(Start the tape recorder AFTER the introductions part of the discussion. This guide includes the topics to be covered and questions that may be helpful in facilitating the discussion. You do NOT have to ask all the questions or follow the order given in the guide. Major topic areas and questions are indicated in Bold.)
II. INTRODUCTIONS

First let’s get acquainted. Let’s go around the circle and each person can introduce herself. You can tell us your first name, how many children you have, and anything else about yourself that you would like to tell the group. (Members of the research team should also introduce themselves. If the group agreed to the tape recording, you may start recording after this section of the discussion.)

III. DISCUSSION TOPICS

i. HIV/AIDS in the Community
   b. Let’s start by talking about health problems in the community. What are the biggest health problems in this community?
   c. In your community, do you see HIV/AIDS as an important health problem?
      i. Compared to other health problems (such as malaria, gastrointestinal diseases, respiratory diseases, etc.) do you think that HIV/AIDS is an equally, more, or less important health problem?
   d. In your community, do you think HIV/AIDS is related to certain lifestyles?
   e. In your community, do you think HIV/AIDS is related to poverty?

I. HIV Risk Behaviors
   a. In your community, what are the best ways to prevent HIV?
      i. For women?
      ii. For men?
   b. In your community, what might people see as a benefit of engaging in extramarital sex?
   c. In your community, what puts people at risk for HIV/AIDS?
      i. Individual choices (i.e. extra marital sex, promiscuity, etc)
      ii. Uncontrollable factors—factors that are not chosen, that are structural (i.e. living in a fishing community, poverty, etc)
   d. What is the role of jaboya in spreading HIV? Jaboya is defined as a relationship where fish and sex are both exchanged.
      i. Why do people practice jaboya?
      ii. What types of people practice jaboya?
      iii. Can illness lead to jaboya? Why?

J. HIV on Mfangano
   a. What is the effect of HIV on your community as a whole?
      i. Household (family),
      ii. Economically,
      iii. Emotionally,
      iv. Physically,
      v. Earning Income,
      vi. Getting Enough Food)
   b. What role does the fishing industry play in contributing to HIV levels on the island?
c. Why do you think HIV/AIDS exists in Mfangano Island?
d. Why do you think levels of HIV/AIDS are so high?
e. In your community, when people become HIV positive, is it their own fault?
f. In your community, do married men and women often live apart? Why?
   i. What is the effect of this situation?
   ii. How does living apart increase the spread of HIV/AIDS?
g. How does polygamy in your community impact the spread of HIV/AIDS? Why?
h. How does wife inheritance impact the spread of HIV/AIDS? Why?

K. HIV Testing
   a. In your community, what is the main way through which people in your community learn their HIV/AIDS status?
   b. What reasons make people in your community choose to be tested for HIV/AIDS (go to VCT)?
   c. What reasons make men in your community choose NOT to be tested for HIV/AIDS (go to VCT)?
   d. What reasons make women in your community choose NOT to be tested for HIV/AIDS (go to VCT)?
   e. In your community, are people encouraged to get tested for HIV? Why?
   f. In your community, what do people feel about the quality of the HIV testing service that they choose to go to?
   g. Do people trust the HIV test? How many times do people get tested before they accept the results?

L. HIV Care and Treatment
   a. In your community, how do people feel about the treatment for HIV that they receive?
   b. Is it easy or hard to access medications? Why?
   c. Do HIV positive people experience any challenges at the health facilities? Why?
   d. Why might people stop or default on their medications?
   e. When people get sick in your community, what kinds of support do they normally receive (i.e. emotional, help with medical fees, sharing food, etc)?
      i. Do people with HIV have more or less support? Why?
      ii. Who provides support for people with HIV?
   f. If children have HIV, is more support offered than for adults with HIV?
   g. Do you think the amount of support an individual has impacts whether someone discloses their HIV status to the community?
      i. What types of support is asked for and offered?
      ii. Is stigma a barrier for a household to ask for more support?

M. HIV/AIDS Disclosure
   a. Is it important for people to reveal their status? Why?
   b. Do you think many people have disclosed their HIV status openly in your community?
      i. What risks are there for disclosing one’s status? Why do you think those risks exist?
      ii. What benefits are there for disclosing one’s status?
c. In your community, are people more likely to disclose their HIV status to their family members? Friends? Neighbors?

d. Do you think it is important for one to disclose his/her status to their partner? Why?
   i. If the man is positive, is he likely to tell?
   ii. If the woman is positive, is she likely to tell?

e. In your community, what are the consequences when one partner in a relationship discloses his status to the other partner? (ASK if there good consequences and bad consequences)

N. HIV/AIDS Beliefs

   a. Are there any widespread misconceptions in your community about HIV/AIDS?

   b. In your community, do people believe there is a cure for HIV/AIDS?

   c. In your community, do people believe there is a treatment for HIV/AIDS?
      i. What are the benefits of this treatment?
      ii. What are the problems with this treatment?

   d. Do people believe in spiritual or traditional healing (Manyasi, loliondo)? In biomedical treatments?

O. Sources of HIV/AIDS Information

   a. In your community, what are the main sources of information about HIV/AIDS?
      i. Is the information you receive from different sources similar?
      ii. Do you trust some sources more than others? Why?
      iii. Are these sources reaching the majority of the community?

   b. In your community, is there any information that would be useful for people to learn about HIV/AIDS?
      i. What is the best way to deliver this information to people?

P. Ideas about HIV/AIDS Support

   a. What assistance programs would you like to see in your community for HIV positive people? For everyone?

   b. What type of assistance or services would make it easier for a person to disclose their HIV/AIDS status?

IV. CLOSING

Thank you very much for your time. Your responses will be very helpful for improving health services for Kenyan families. (Record participant characteristics on form.) (Correct any important misconceptions and provide referrals to VCT, PMTCT, or ARV services, if appropriate.)
I. TIMO NG’ERUOK.
Nyinga en_________________. Atiyo gi jo Kenya Medical Research Institute, mbalariany mar California San Francisco manie United States, Kod Ekialo Kiona Center e chenro madwaro ng’eyo gik matimore e Chula mar Mfangano. Ka wan kod (Nyinge jandiko). Dwaher mar wuoyo kodu kuom gik matimore e gweng’, moriwore gi ng’eyo maber mar jogweng’ kuom kute mag ayaki, pach jogweng’ kuom tuo no, timbe jogweng’ kaluwore gi tuo no, kanyakla gi paro kod duoko kuom chenro mag kit thieth mosebende mag kute mag ayaki kod yor yudo wach e wi kute mag ayaki. Gikone, weche ma uchiwo ibiro tigo kuom nyiso gik mosetim mondo otieng/ogur kendo oting’ malo/omed chenro mag dongruok ei Mfangano.

Dwaher ma
r wuoyo kodu kuom gik matimore e gweng’. Ok wadwar wach mawuoyo kuom ng’ato ang’ata kata wach momaki in iwuon. Onge duoko marach kata maber ne penjo mabiro penjo, kendo bende in thuolo mar weyo mokiduko gima ineno ni ok inyal duoko. Wan gi geno ni ng’at ang’ata ni thuolo mar golo pache.

Twak ma kawuononi gin weche maling’ling’. Ok wabitudi gi wach moro amora miwacho kendo ka wandiko wach kuom maling’ling’ ok wabitiyo gi nying ng’ato ang’ata. Wakwayi ni kik iwach wechegi kiwuok oko mar odni.
Wachni/Twagni ok bikawo thuolo malach (kinde madirom seche ariyo). Ka in gi penjo e wi wachho kata e wechego wanyalo konyi yudo duoko bang’ tieko twagni kanyakla. Mondo ukonya e winjo twakni, daher mar kwayo thuolo mar ndiko kendo kawo wechegi kod masindni. Bende un thuolo mar twak? Bende wan gi thuolo mar mako wecheu gi masindni?

Maluwo mano, dwakwau ni mondo uyie bedo e twagni. (Pong’ kalatasni kendo ng’ato ka ng’ato moyie bedo e twak mondo oket sei).
Kapok wachako, nitie/wan gi chike moko mag kanyakla. (Yangi chike mag twak mar kanyakla).

(Yaw masindni bang’ timo ng’eruok e twak). Okang’ni oriwo thuond weche maibiro wuoye kendo penjo manyalo konyo e twagni. Ok ochuno ni nyaka ipenj penjo te kata ilugi kaka gin no. Thuond weche kod penjo onyis e ndiko modhienyore.

II. TIMO NG’ERUOK.

III. THUOND WECHE MAG TWAK.
A. Kute Mag Ayaki e Gweng’.

Appendix: C.b
a) Wawuo mokwongo kuom chandruok mar ngimawa e gweng’. Gin chanduok mage madongo mag ngimawa e gweng’ni?

b) E gweng’u, bende ineno kute mag ayaki ka gima en chandruok mar ngima monengo ong’I maber?
   i. Pimane chandruok mag kute mag ayaki kod chanduok mamoko machalo mag malaria, touché mag ich, touché mag kor, gimamoko. Bende uparo ni kute mag ayaki nitie e rapim marom, mang’eny koso matin ne chandruok mag touché mamokogi?

c) E gweng’u, bende uparo ni kute mag ayaki otudore gi kit dak mag ji?

d) E gweng’u, bende uparo ni kute mag ayaki otudore gi chan/dhier?

B. Timbe Manyalo Keto Ng’ato E Okang’ Mar Yudo Kute Mag Ayaki.

a) E gweng’u, ere yore mabeyo mag ritruok kuom yor yudo kute mag ayaki?
   i. Kuom Jomamine?
   ii. Kuom Jomachwo?

b) E gweng’u, ere gik ma ji neno kaka ohala kuom bedo gi jaherani oko mar kend/osiep?

c) E gweng’u, ang’o maketo ji bedo e okang’ mag yudo kute mag ayaki?
   i. Yiero mar ng’ato (kaka terruok gi ng’ama ok jaodi kata osiepni migeno, chode, gimamoko).
   ii. Gik ma ok nyal geng’ kaka dak e gweng’ milupe, chan/dhier, gimamoko.

d) En okenge kata ang’o ma jaboya timo makelo landruok mar kute mag ayaki? Jaboya ilero kaka tudruok e kind jomaluwo rech kod joma gi terorego.
   i. Ang’o momiyo ji bedo joboya?
   ii. Gin jomachal nade mabedo joboya?
   iii. Bende tuo nyalo keto ng’ato bedo jaboya? Nikech ang’o?

C. Kute Mag Ayaki E Chula Mar Mfangano.

a) Ere gima kute mag ayaki kelo/timo e gweng’u?
   i. ne joot,
   ii. e yor pesa,
   iii. e yor jiwruok mar chuny,
iv. e yor del maoko,
v. e yor yuto,
vi. e yor yudo chiemo moromo).

b) En ang’o ma lupo timo kuom landruok mag kute mag ayaki ei chula ka?
c) Ang’o momiyo iparo ni kute mag ayaki yudore e chula mar mfangano?
d) Ang’o momiyo iparo ni landruok mag kute mag ayaki medore/ni malo e gweng’u?
e) E gweng’u, ka ji obedo gi kute mag ayaki, bende en kethogi/makosagi?
f) E gweng’u, bende chwo mokendo kata mon mokendi nyalo dak kuonde mopogore? Nikech ang’o?
   i. Ang’o ma dak mopogoreno kelo?
   ii. Ere kaka dak mopogore medo landruok mag kute mag ayaki?
g) Ere kaka doo ma e gweng’u kelo/timo e landruok mag kute mag ayaki?
h) Ere kaka tero mon nigí tudruok kuom landruok mag kute mag ayaki?

D. Ng’eyo Chalni kuom Kute mag Ayaki.

a) E gweng’u, en yo mane maduong’ ma jo gweng’u puonjore kata ng’eyogo chalgi kuom kute mag ayaki?
b) Ang’o momiyo jogweng’u yiero ni mondo ging’e chalgi kuom kute mag ayaki?
c) Ang’o gini e gweng’u mamono chwo dhi e pim mar ng’eyo chalgi kuom kute mag ayaki?
d) Ang’o gini e gweng’u mamono mon dhi e pim mar ng’eyo chalgi kuom kute mag ayaki?
e) E gweng’u, bende ijiwo ji mondo odhi e pim mar ng’eyo chalgi kuom kute mag ayaki?
f) E gweng’u, ang’o ma ji paro/winjo kuom okang’ magiyiero dhiye mar pim mar kute mag ayaki?
g) Bende ji oyie gi pim mar ng’eyo chalgi kuom kute mag ayaki? En nyadidi ma ipimo chal ji kapok giyie gi duokono/duokogi?

E. Kawo Okang’ Mar Rit Kod Thieth Kuom Kute Mag Ayaki.

a) E gweng’u, ere kaka ji kawo/winjo wach mar thieth mar kute mag ayaki magiyudo?
b) Bende nitie yot koso pek e yudo yien? Nikech ang’o?

c) Bende joma negi kute mag ayaki yudo/bedo gi chandruok moroamora kuonde thieth? Nikech ang’o?

d) Ang’o momiyo ji nyalo weyo dhi kawo yien kata muonyo yien?

e) Ka ji obedo matuo e gweng’u ere kit kony magithoro yudo? (Kuom ranyisi, jiwruko mar chuny, kony mar pesa ming’iewo goyo yath, pogo chiemo, gimamoko).
   i. Bende jok man gi kute mag ayaki yudo kony mang’eny koso matin?
   ii. Ng’ano gini machiwo kony ne jogo man gi kute mag ayaki?

f) Ka nyithindo ni gi kute mag ayaki, giyudo kony mang’eny moloyo ka jomadongo e manigi kutego?

g) Bende uparo ni kit kony ma ji nigodo/yudo nyalo miyo giful chalgi kuom bedo gi kute mag ayaki e gweng’?
   i. En kit kony mane mikwayo kendo ichiwo?
   ii. Bende luoro mono joot kwayo kony?

F. Fulruok Kuom Kute mag Ayaki.

a) Bende en gima ber fulo chalni kuom kute mag ayaki? Nikech ang’o?

b) Bende iparo ni ji mang’eny osefulo chalgi kuom kute mag ayaki ayanga e gweng’u?
   i. Gin chandruok mage magiyudo kuom fulore ayanga kuom kute mag ayaki? Ang’o makelo chandruokgo?
   ii. Bende nitie Ohala/ber ma ng’ato yudo kuom fulruok kuom kute mag ayaki?

c) E gweng’u, bende ji ohero fulore kuom kute mag ayaki ne joutegi? Osiepegi? Jirendegi?

d) Bende iparo ni en gima ber mondo ng’ato ofulni wadgi(osiepne kata jaode) chalne? Nikech ang’o?
   i. Ka dichwo niggi kute mag ayaki bende onyalo fulore ne jaode?
   ii. Ka miyo niggi kute mag ayaki bende onyalo fulore ne jaode?

e) E gweng’u, ang’o manyalo timore kadipo ni achiel kuom joma okendore ofulore kuom chalne ne wadgi? (Penj ka nitie gik mabeyo kata maricho matimore)
G. Paro ma ji nigodo kuom Kute mag Ayaki.
   a) Bende nitie paro moko mokadiera moselandore kuom wach kute mag ayaki e gweng’u?
   b) E gweng’u, bende ji nigi paro ni nitie thieth magolo kute mag Ayaki chuth?
   c) E gweng’u, bende ji nigi paro ni nitie thieth mathiro kute mag Ayaki?
      i. Ere ber mar thieth mar thiro kute mag ayaki?
      ii. Ere chandruok miyudo kuom thieth mar thiro kute mag ayaki?
   d) Bende ji paro ni niti yor lemo kata yor thieth nyaluo makelo chang (Loliondo, manyasi)? Thieth mar osutal? Bende ji tiyo kod gi gite?

H. Yore Kata Kuonde Miyude Weche/Puonj Kuom Kute Mag Ayaki.
   a) E gweng’u, gin yore mage miyudogo weche/puonj kuom kute mag ayaki?
      i. Bende weche/puonj muyudo koa kuonde mopogoreopogore chal?
      ii. Bende nitie kuonde miyude wechegi/puonjgi kuom kute mag ayaki muyiego moloyo moko? Nikech ang’o?
      iii. Bende yore mag yudo weche/puonj kuom kute mag ayaki chopo ne jomang’eny e gweng’?
   b) E gweng’,u bende nitie weche/puonj minyalo tigo gi ji mar puonjruok kuom kute mag ayaki?
      i. En yo mane maber ne chiwo/nyiso ji weche mag kute mag ayaki?

I. Paro/weche kuom Kony miyudo gi jok man gi Kute mag ayaki.
   a) Gin chenro mamoko mage madiher neno kokel e gweng’u ne joma nigiti kute mag ayaki? Ne ji duto?
   b) Kit kony kata puonj mage manyalo kelo yot ne jogo man gi kute mag ayaki ulo chalgi?

IV. LORO.
Erokamano uru ahinya kuom thuolou. Duoko meku biro konyo ahinya e tingruok malo tije mag thieth ne Jokenya. (Record Participant characteristics on form). Tem ng’eyo winjo madibede marach kendo chiw ne jo VCT, PMTCT, kata ARV services, kaka nyalore.