

Impact of HIV-Related Stigma and Discrimination on  
HIV Testing Behaviors, and Interventions to Improve HIV Testing Uptake,  
in Northern Tanzania

by

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## ABSTRACT

Access to testing for the human immunodeficiency virus (HIV), as well as other care services related to HIV/AIDS, have greatly improved in Tanzania over the last decade. Despite the country's efforts to increase the number of individuals who get tested for HIV annually, it is estimated that only 52.2-70.0% of people living with HIV (PLWH) knew their HIV positive status at the end of 2017. In addition, research in Tanzania has shown that HIV-related stigma and discrimination are widespread and contribute to low uptake of HIV testing and non-adherence to antiretroviral treatment (ART). In order to achieve the goals set forth by the Government of Tanzania and the Joint United Nations Programme on HIV/AIDS (UNAIDS), as well as move towards an AIDS-free generation, a deeper understanding of the stigma-related barriers to seeking an HIV test is necessary. This research aims to better understand the relationship between HIV-related stigma and attitudes towards HIV testing among community members in Northern Tanzania. In addition, it looked at the specific barriers that contribute to low uptake of HIV testing, as well as the impact of social networks on an individual's motivation and willingness to get tested for HIV. In this research, community members in Meru District (N = 108, male = 69.4%, female = 28.7%) were surveyed using various validated instruments that covered a range of topics, including knowledge of HIV/AIDS, testing attitudes, and perceived risk of HIV infection. The mean overall score for correct answers on the knowledge measure was 69.8% (SD = 16.4). There were no significant group differences between individuals who had ever tested and individuals who had not tested in relation to HIV/AIDS knowledge or HIV testing attitudes. The factors that were significantly associated with getting an HIV test were knowing someone who had

previously tested ( $p = 0.003$ ), as well as openly discussing HIV testing within one's social group ( $p = 0.017$ ). Participants also provided qualitative responses for barriers to receiving an HIV test, motivations for getting tested, and suggested interventions for improving HIV testing uptake. The goal of this research is to develop recommendations for interventions that are better informed by attitudes and motivations for testing.

## DEDICATION

This body of work is dedicated to those who are affected by HIV/AIDS globally. It is my dream and passion that this work will contribute to the reduction of HIV-related stigma in communities around the world, allowing for more freedom, the ability to live full and healthy lives, and the achievement of an AIDS-free generation.

This work is also dedicated to my family and friends all over the world, from whom I have received the support and love necessary to explore, discover, grow, and thrive.

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## CHAPTER 1

### INTRODUCTION

**Background.** Research in Tanzania has indicated that much of the adult population holds views that stigmatize people living with HIV/AIDS. Despite this, there has not been a significant amount of research in the country that focuses on the relationship between an individual's perception of HIV-related stigma, their attitudes towards HIV testing, and their willingness to get tested for HIV. As governments across Africa continue to scale up Antiretroviral Therapy (ART) and encourage nationwide testing programs in an attempt to end the epidemic, significant challenges remain – among the first: individual willingness and ability to get an HIV test in the face of stigmatization at each level of the community.

This research investigates the ways in which HIV-related stigma impacts willingness and ability for an individual to get tested for HIV in Northern Tanzania. Additionally, these findings aim to develop a broader understanding of the attitudes of community members towards HIV testing, as well as investigate the stigma-related underlying barriers that result in individuals choosing to not get tested for HIV. To do this, the research explores the interconnected relationships between testing behaviors, perceived risk of HIV, knowledge of the disease, perceived and experienced stigma, HIV testing attitudes, and social networks.

This research also looks at how the cycle of stigma can be broken in order to improve health seeking behaviors, as well as solicits advice from surveyed community members about interventions that might be successful. Through this, the research hopes

to understand more deeply, consider more carefully, and develop more powerfully interventions that will improve testing uptake for HIV/AIDS.

**Rationale and Goals.** This research explored the following questions: How do stigma and discrimination, as well as attitudes towards HIV testing, impact an individual's willingness to get an HIV test in Northern Tanzania? In addition, are there aspects of an individual's social network that provide an environment for positive acceptance of an HIV test? The expected development endpoints for this study are as follows:

- A greater regional and national understanding of the issue of HIV-related stigma, particularly related to the experiences of young people
- A greater regional understanding of the underlying factors that inhibit willingness to get tested for HIV, mediating factors associated with HIV stigma, and approaches to break the cycle of HIV stigma
- A greater understanding of the availability and accessibility of HIV testing in the region, and individual perceived barriers and motivations to get testing for HIV

Developing a better understanding of community-level HIV-related stigma will allow for better decision making about designing intervention programs that target context-specific stigma and encourage testing in a more powerful way. The goal is to develop an evidence-based curriculum and intervention for targeting HIV-stigma in an effort to measurably reduce stigma at all levels of community. By reducing stigma in the community, individuals living with HIV will experience less discrimination, community

members will be more likely to seek testing services, and countries will be one step closer to achieving national and international goals.

**Stakeholders.** This research was completed in collaboration with Arizona State University, USAID Research and Innovation Fellowship Program, HEAL International, and Meru District Hospital in Arusha, Tanzania. The research was carried out by a master's student in Biology & Society at Arizona State University. HEAL International has been working in Meru District for the past 10 years, collaborating with the community to develop strong HIV/AIDS prevention programs aimed at increasing positive health behaviors and decreasing stigma. Meru District Hospital is committed to providing care and treatment for individuals living with HIV/AIDS and are stakeholders in understanding the underlying reasons why individuals do not access testing or adhere to antiretroviral treatment.

## CHAPTER 2

### LITERATURE REVIEW

**Literature Review.** HIV/AIDS is a major public health concern in Sub-Saharan Africa; 69% of all individuals who are living with the disease globally are found in the region, and the region accounts for 70% of all AIDS-related deaths (UNAIDS, 2018). Additionally, eastern and southern Africa accounted for 16% of the new HIV infections in 2017 (UNAIDS, 2018). In order to cope with these devastating statistics, African governments, including Tanzania, have greatly increased access to testing, treatment, and care services for individuals who are living with HIV.

*HIV/AIDS in Tanzania.* According to UNAIDS, the adult HIV prevalence rate in Tanzania (ages 14-59) was 4.7% in 2016, with regional prevalence ranging from 0.2% (Kaskazini Unguja, Zanzibar) to 15.4% (Njombe). Gender disparities between male prevalence (3.7%) and female prevalence (6.2%), as well as the increasing prevalence of HIV infection in young girls in some parts of the country and the acquisition of the infection for young girls at an earlier age than boys, is alarming (Tanzania HIV/AIDS Malaria Indicator Survey, 2012). Reported statistics on the number of individuals in Tanzania who are living with HIV and know their status vary, however it is estimated that only between 52.2-70% of individuals who are HIV positive know their status (UNAIDS, 2016 & Tanzania HIV Impact Survey, 2017). Only 62% of individuals living with HIV in Tanzania are on antiretroviral treatment (UNAIDS, 2016).

In an attempt to overcome the effects of the AIDS epidemic in the country, international agencies, local non-governmental organizations, and the Tanzanian government have collaborated on various efforts over the past three decades to increase

knowledge of HIV/AIDS, bolster access to testing and care services throughout the country, and decrease HIV-related stigma and discrimination. In 2014, UNAIDS released the global 90-90-90 plan to end the AIDS epidemic, which states that by 2020, 90% of people living with HIV will know their status, 90% of people living with HIV will be on sustained antiretroviral therapy, and 90% of people living with HIV will have viral suppression (UNAIDS, 2014). In partnership with the President's Emergency Plan for AIDS Relief (PEPFAR), a new Country Operational Plan for Tanzania was put in place in 2017 and provides recommendations for scaling up education, testing, and treatment services in all districts across the country (PEPFAR, 2017). This plan comes on the heels of various other national guidelines, including the most recent Health Sector HIV Strategic Plan IV (2017), and other strategies for tackling the AIDS epidemic in the country.

In many ways, the efforts of the government and other agencies have been successful. Tanzania began providing HIV care services and ART universally free of charge in the public sector in 2004 through funds provided by the government and donors such as PEPFAR and the Global Fund to Fight AIDS, Tuberculosis, and Malaria (Souteyrand et al., 2009). This effort has greatly increased the number of individuals who are accessing care services and initiating HIV treatment in Tanzania. According to the Department of Policy and Planning, there were 2,672 care and treatment centers offering HIV services (including free HIV testing) in 2013 (List of HIV Care and Treatment Centers, 2013). Presumably, that number has since increased. In addition, the government has implemented other strategies such as scaling up HIV testing, improving pre- and

post-test counseling, and preventing mother to child transmission by heavily investing in infrastructure for HIV treatment services for pregnant women (NACP, 2018).

In early 2018, the Tanzanian Deputy Minister of Health announced that, through PEPFAR, an additional \$512 million would be committed during the year to combat HIV/AIDS in the country (US Embassy Dar es Salaam, 2018). Ummu Mwalimu, the current Minister of Health, also stated that the Government of Tanzania is committed to employing new strategies that will bring more people, especially males, to HIV testing (@umwalimu, 2018).

The Government of Tanzania hopes to have control over the AIDS epidemic by late 2019 (PEPFAR, 2017). Despite the relatively high ratio of centers that offer HIV testing and treatment services (roughly 1.9 centers per 1,000 people living with HIV), only about 52.2-70% of people living with HIV know their status, and only about 60% of individuals who are HIV positive are currently accessing antiretroviral therapy (UNAIDS, 2016 & Tanzania HIV Impact Survey, 2017). While it's clear that structural and logistical challenges still exist to meeting the ambitious goals for an AIDS-free generation, one of the most challenging barriers is stigma and discrimination towards individuals living with HIV/AIDS, which greatly impacts an individual's willingness to get tested and access treatment. Targeting stigma and discrimination through education and national campaigns will support the country in achieving the 90-90-90 goals.

*HIV-related Stigma and Discrimination.* There are many definitions of stigma that describe the experiences and perceptions of individuals in a community. In this research, stigma is defined as “an attribute, behavior, or reputation which is socially discrediting in

a particular way” (Goffman, 1963), as this definition is often used when discussing health-related stigma. If someone is stigmatized, they are often seen as a disgrace and/or perceived to have less value or worth in the eyes of others (NACOPHA, 2013). The stigma associated with HIV is often reinforced by the association of HIV and AIDS with already “marginalized and stigmatized behaviors, such as sex work, drug use and same-sex and transgender sexual practices” (NACOPHA, 2013).

Additionally, there are a variety of types of stigma, including internal stigma (often referred to as self-stigmatization), received or external stigma, and associated stigma, as well as various contexts in which stigma can occur (Holzemer et al., 2007). For example, people living with HIV (PLWH) might experience stigma in their community or living environment, at their place of work, in the healthcare system, or as a result of their own perceptions and thoughts (Holzemer et al., 2007). Nyblade et al. (2005) specified four distinct domains of stigma related to HIV - fear of causal contact, moral values of shame, blame and judgment, discrimination and disclosure - and these have been widely used to develop measures for understanding stigma at both the individual and the community level.

Stigma can have devastating implications for an individual’s health, and often is a major source of health inequalities in a society. The presence of stigma impacts an individual’s quality of life and can create life-inhibiting emotional, psychological, relational or material outcomes, especially for people living with HIV (Chidrawi et al., 2016).

Individuals in Tanzania are not immune to the effects of HIV-related stigma, and research conducted in the country has tried to better understand the sources of this stigma



and the impacts it has on health seeking behaviors and health outcomes. Researchers have identified that individuals living with HIV in Tanzania experience various forms of verbal stigma, social stigma, and perceived stigma, as well as disapproval, rejection, inequitable access to care, and sub-optimal services in healthcare settings (UNAIDS, 2014, Mhode & Nyamhanga, 2016). Additionally, PLWH report experiencing forms of discrimination and segregation, blame and rejection, mistreatment by healthcare providers, low self-esteem, and changes in relationships (Mhode & Nyamhanga, 2016, NACOPHA, 2013). Stigma and discrimination continue to undermine effective responses to the AIDS epidemic, and stigma remains a major barrier to seeking HIV testing and treatment services (UNAIDS, 2014, Rao et al., 2007, Weiss and Ramakrishna, 2001, Newman et al., 2002), resulting in delays to access care and consequently increasing illness and death. Stigma often forces people living with HIV to not seek care and treatment services and discourages those who have tested positive to disclose their status, which “interferes with their coping process” and can lead to concealing their health status and refusing to seek treatment that can extend their life (Nyblade & MacQuarrie, 2006 & NACP, 2008).

Not only is stigma something that is felt by PLWH, but it is also highly reported that community members in Tanzania hold stigmatizing views towards individuals who are HIV positive. According to a study by the National Aids Control Programme, stigma is still rampant among members of the community surrounding health facilities, which limits patients’ willingness to get tested and adhere to ARVs (NACP, 2008). Research by the Tanzania Commission for AIDS also indicates that 75% of women and 60% of men express stigmatizing attitudes or beliefs towards HIV positive individuals (2013). It’s

clear that stigma and discrimination are pervasive and debilitating; despite over three decades of prevention education programs and the provision of care services and antiretroviral treatment, individuals in communities still hold stigmatizing views of people who are living with HIV.

*HIV Testing Services and the Impact of HIV-Related Stigma.* As noted above, Tanzania has set specific objectives to increase access to, and knowledge about, HIV testing services throughout the country, including the provision of pre- and post-test counseling. In mid-2018, a nationwide campaign was launched in Dodoma, Tanzania's capital city, to encourage all Tanzanians, especially men and youth, to get tested for HIV. This campaign, titled "Furaha Yangu" (meaning, "my pleasure" in Swahili) was officiated by Tanzania's Prime Minister H.E. Kassim Majaliwa and was set to cover 20 regions in the country (International Labour Organization, 2018). This campaign was launched in response to the relatively high number of individuals who are living with HIV and do not know their status.

In Tanzania, an individual can access HIV testing at a number of health locations. In rural areas, individuals can go to a local dispensary in their village or ward and receive a free HIV test. In peri-urban and urban areas, HIV testing can be accessed at a health clinic, at a private or government-owned laboratory, and at a private or governmental hospital. District and regional hospitals also offer off-site testing days, where nurses and physicians travel into remote areas, or areas that are highly affected by HIV/AIDS, and facilitate education and testing services.

Despite the increase in efforts to offer access to HIV testing services, there is little research on the relationship between HIV-related stigma and the acceptance and uptake

of HIV tests in Tanzania. Research by Brown, Trujillo & Macintyre (2001), as well as research by Pitpitan et al. (2012), showed that HIV-related stigma can impact seeking an HIV test, and studies from Botswana and Zambia show that high levels of stigma and fear of being mistreated prevent participation in testing and counseling services (Nyblade et al, 2003).

One reason for this could be that individuals hold stigmatizing attitudes towards HIV testing that create an unwillingness to seek HIV testing. To explore this, Boshamer and Bruce (1999) developed a validated instrument for better understanding salient beliefs and attitudes towards HIV Antibody Testing (HTAS). Additionally, individuals have specific motivations for testing that are often linked with their age, education, social support, perceived risk of HIV infection, reported risky behaviors, and life stage (Koku, 2010, Kabiru, 2011). Smoot (2002) and Kalichman (2003) show that attitudes towards testing depend on whether or not someone has previously been tested, and that individuals who have received a test tend to have more positive views than those who have not been tested. Research from Ghana shows that the odds for having ever been tested are higher among individuals with higher levels of education, those in wealthier households, and those with high levels of knowledge of HIV/AIDS (Koku, 2010). It has also been reported that desire for, and uptake of, testing seems to decline with age. Research also shows that, compared to people who had been tested for HIV, individuals who have not been tested demonstrate significantly greater AIDS-related stigma, and often ascribe greater shame, guilt, and social disapproval to people living with HIV (Kalichman, 2003).

Anecdotes from HIV prevention education programs, specifically those led by HEAL International in Northern Tanzania, have also confirmed stigma as playing a major role in seeking an HIV test - people often report being afraid of going to a health clinic to get a test because they are worried about what their family and other members of the community will think of them and their behavior. People also indicate that they would rather “not know” the outcome of their test because of the misconception that an HIV positive diagnosis automatically means death.

Predictors of positive health seeking behaviors, including testing for HIV, vary considerably across populations and settings with respect to various individual, socio-economic, institutional, and structural factors (NACP, 2008, Nsimba et al., 2010 & Semvua et al., 2017). As the Government of Tanzania continues to increase services throughout the country, it will be important to better understand the effects of HIV-related stigma on willingness to get an HIV test. Particularly, it will be important to understand how testing can be encouraged despite the existence of HIV-related stigma in the community.

*Social Support, Coping, and Disclosure.* Although this research doesn't specifically look at mechanisms for coping with, or disclosing, an HIV positive diagnosis, these factors play an important role in understanding how individuals view HIV/AIDS in their community. Additionally, the existence of social networks can impact an individual's willingness to get tested for HIV and can provide a means for widely encouraging HIV testing at the community level.

Multiple studies have looked at the way that PLWH cope with their diagnosis, specifically in relation to experienced stigma from social networks or their community.

Mhode & Nyamhanga (2016) found that individuals often overcome HIV-related stigma through spiritual devotion, acceptance of the illness, seeking information or conversation about HIV/AIDS with individuals in their community, and preemptive disclosure.

Additionally, religious coping is known to be positively related to acceptance of an HIV-positive diagnosis, especially in Tanzania (Lyimo, 2014, Makoae, 2008).

Social networks play a particularly important role in creating an environment for conversations about HIV testing and treatment, disclosure of an HIV status, and coping with the stigma related to an illness. If an individual feels as though they have strong social support from their friends, family, and community, they seem to be more likely to engage in positive health seeking behaviors and hold less fear and stigma about the outcomes of their health status. In fact, social networks and focus groups are reported to reduce physical and social isolation that results from an HIV positive status, and can provide an improved sense of self-worth in an individual's life (Majumdar, 2004, Makoae & Nyblade, 2003). Additionally, talking to others builds networks that can provide a way for individuals to share their stories, develop friendships, reduce fears related to HIV, and can serve as a protective factor to the effects of stress on health. However, as previously discussed, community members often do hold stigmatizing views of individuals living with HIV, and therefore community-level support for getting an HIV test or seeking HIV care services could be debilitated.

With regards to disclosing an HIV status, research from Lyimo (2014) notes that the more open someone is about their HIV status, the less self-stigma they experience. Additionally, some respondents in a study by Makoae (2008) share that they felt relieved by disclosing their HIV status and felt positive about being able to talk about their status

in the community. In the context of decreasing stigma related to HIV testing, knowing that someone is living with HIV (meaning that person has disclosed their status) could serve as a correlate for seeking an HIV test.

A literature review regarding stigma is not easily synthesized, and often times, studies of stigma are not completed at a country-wide level, limiting the availability of generalizable outcomes. An excess of literature in the field focuses on defining and understanding the types of stigma that exist for PLWH, as well as the confounding factors that increase stigma, such as poverty, lack of education, and living in rural areas (Amuri, 2011). Studies also look at the relationship between stigma and mental health, the effects of social networks, and the connection between stigma and religion. While there is a large amount of data about HIV stigma in Tanzania, the effects of stigma and discrimination are still visibly present. Individuals in the community are not not adequately accessing health services, particularly HIV testing. Understanding the effects of stigma on these health behaviors will allow for the development of intervention approaches to increase health behaviors and ultimately reach the 90-90-90 goals.

**Theoretical Framework.** This formative research is guided by the Socio-Ecological Model and uses qualitative and quantitative methods to gather information for potential intervention design. This model provides a dynamic and encompassing framework for understanding various levels of behavior change, and what influences that change, ranging from an individual to a structural level. Kaufman et al. (Figure 1) describes some of these influences, specifically related to HIV prevention, treatment, and care (2014). The *individual* level includes perceptions, beliefs, and attitudes, while the

*interpersonal* level is comprised of family influences and social support. The *community* level includes the broader community, including group norms, and the *institutional* level focuses on factors within the health systems, such as confidentiality and resources (specifically important to HIV testing). Lastly, the *structural* level describes macro-factors that affect behavior, such as the economy, policies, and funding (Kaufman et al., 2014).

There is precedent for using the Socio-Ecological Model to describe HIV testing behaviors, as well as to guide and understand HIV prevention interventions, stigma reduction, and health seeking behaviors. Dyson and colleagues (2018) found that individual, interpersonal, social, and organizational factors all play a role in an individual's testing behaviors and attitudes towards testing. This research looks at various levels to better understand individual HIV testing behaviors. Specifically, it focused on the individual level (knowledge of HIV, motivation, risk perception, attitudes toward HIV tests, and outcome expectancies), the social level (social support, communication with friends/ family, social networks), the community level (stigma about HIV), the institutional level (confidentiality/ privacy), and the structural level (access to services).

## CHAPTER 3

### RESEARCH METHODS & DESIGN

**Research Design.** This formative research is dedicated to investigation, discovery, and breakthrough in the area of HIV stigma and testing. Quantitative and qualitative research approaches were used to assess a number of topics in this regard, including HIV knowledge, testing behaviors, stigma, attitudes towards HIV testing, risk analysis, and social networks. The research consisted of self-report surveys with community members in Meru District that included both multiple-selection and open-ended questions.

**Study Site.** Meru District is located within the Arusha region in Northern Tanzania. The 2012 population census indicates that the population of Meru District was 268,114. It has undoubtedly grown since then. Meru District is located on the southern slope of Mt. Meru, the third tallest mountain in the country. The district's economy is almost entirely based on the growth and sale of agricultural products and livestock raising. The district boasts one District-level, government-operated medical hospital (Meru District Hospital), and a number of smaller-level health clinics and village dispensaries, which provide access to services for basic medical needs. Meru District Hospital is home to the district's only government-operated Care and Treatment Center (CTC), which provides HIV testing, pre- and post-test counseling, antiretroviral therapy, and care for individuals who are living with HIV/AIDS.

The current HIV prevalence rate in Arusha is around 1.9%, and has declined over the past decade (National Bureau of Statistics, 2016). Despite this, major barriers still



exist to accessing prevention, care, and treatment services, particularly for individuals who live far from medical facilities. In addition, there are high amounts of reported stigma towards people who are living with HIV/AIDS in the area.

This location was selected because previous research has identified that individuals in the district hold values and beliefs about HIV/AIDS that breed an environment for stigma, and since the region has a large youth population, these stigmatizing views may impact future testing campaigns and education programs in the area. Additionally, HEAL International, one of the stakeholders in this research, operates within Meru District and offers sexual and reproductive health education in primary and secondary schools, universities, and the community. HEAL International and Meru District Hospital work in partnership to achieve the goal of an AIDS-free generation.

**Inclusion Criteria.** Inclusion criteria were intended as follows: participants need to be over 18 years of age, conversant in either Swahili or English, and willing to give informed consent for participation. Surveys were completed in private, and no identifying information was used. Individuals were recruited for this study through local village leadership, community relationships, and universities. Individuals were selected for and approached at random from these sources based on the above inclusion criteria.

**Sample Size/ Participants.** A total of 115 participants in Meru District gave consent to participate in this research and completed a series of self-report surveys. Of these surveys, 108 were available for analysis and 7 surveys were significantly incomplete and not included. Participants were recruited for the survey through

convenience sampling of individuals in the surrounding community and on local college campuses. Sociodemographic variables were adapted from the Tanzanian Demographic and Health Survey (DHS) (National Bureau of Statistics: Tanzania and ORC Macro, 2005). Characteristics of respondents are shown in Table 1.

<b>Table 1: Summary of sociodemographic characteristics of participants (N=108), including testing behavior</b>				
<b>Characteristics</b>		<b>Mean or %</b>	<b>Std. Deviation</b>	<b>Min, Max</b>
Gender	Male	69.4		0, 1
	Female	28.7		0, 1
Age		22.23	2.167	18, 30
Ever Married	No	92.6		0, 1
	Yes	6.5		0, 1
Children	No	88.9		0, 1
	Yes	7.4		0, 1
Household Size		5.0	3.954	1, 30
School Level	Primary School	0.9		1, 6
	Secondary School	5.6		1, 6
	A-Levels	13		1, 6
	Diploma	39.8		1, 6
	Bachelors	25.9		1, 6
	Masters	0.9		1, 6
School Type	Public	58.3		1, 3
	Private	33.3		1, 3
	Both	4.6		1, 3
Employment Status	No	91.7		0, 1
	Yes	7.4		
Religion	Christian	79.6		1, 4
	Muslim	15.7		
	Lutheran	0.9		

	Roman Catholic	1.9		
Ever Tested	No	23.1		0, 1
	Yes	76.9		0, 1
Will Test in Future	No	12.0		0, 1
	Yes	83.3		0,1
Sexual Partners	Male	1.10	1.007	0, 5
	Female	.62	.728	0, 2

**Measures.** Mixed-method (quantitative and qualitative) self-report surveys were conducted with all participants who consented to participate in the study. All surveys measures were team-translated from English to Swahili, and a second translation team back-translated them from Swahili to English. In all cases, surveys did not collect any identifying information. Data was collected without the researchers knowing the names of respondents or being made aware of any unique identifiers attached to the data. See Appendix 1 for full list of survey questions in English.

*HIV Testing Behaviors.* To assess individual testing behaviors, participants were asked to respond to a series of questions about whether or not they had been tested in the past and whether or not they would get tested in the coming 12 months. If participants reported that they had been previously tested, they were asked to share the date and location of their last HIV test, how many times they had ever been tested, and whether or not they received pre- and post-test counseling at their last test.

*Barriers and Motivations.* In order to better understand the community-level barriers for getting an HIV test, participants were asked to list the top three barriers they believe exist in their community. If participants had ever been tested, they were asked to list their motivations for getting an HIV test in order to better understand the reasons why

they sought an HIV test. The same was asked for individuals who had never received an HIV test. These qualitative responses were coded, grouped, and thematic themes were reported on.

*HIV Risk Analysis.* To identify behaviors that could put individuals at risk for HIV, participants were asked the number of sexual partners that they had in the last three months, as well as how often they used condoms within the last three months (6-point likert-scale responses ranging from ‘always’ to ‘never’). Additionally, to assess perceived risk, participants were asked how likely it was that they had HIV at the time of survey, and how likely they were to contract HIV in the coming three months (3-point likert-scale responses: ‘not likely’, ‘somewhat likely’, ‘very likely’).

*HIV/AIDS Knowledge.* To assess knowledge of HIV/AIDS, participants were asked 9 questions adapted from a USAID survey validated in Tanzania (Nyblade et al., 2005). Items reflected information about HIV transmission, HIV prevention behaviors, and other AIDS related knowledge questions, and were responded to as true, false, or don’t know. The AIDS knowledge test was scored for the number of correct responses, with don’t know responses scored as incorrect. Participants were also asked to identify if they had ever participated in an HIV/AIDS education program. To understand the perceived knowledge of the community, participants were asked how well they believed that their community knew about HIV (3-point likert-scale responses ranging from ‘a lot’ to ‘none’).

*HIV Stigma.* Participants were asked whether they agreed or disagreed (dichotomous response) with a series of 8 statements relating to four domains of HIV-related stigma, including fear of causal contact, moral values of shame, blame and

judgment, discrimination, and disclosure. Statements included “I would play sports with someone who is HIV positive,” “HIV is a punishment from God,” “People with HIV should be ashamed of themselves,” and “People with HIV/AIDS are dirty.” Questions related to HIV stigma were adapted from the Stigma Indicator Community Questionnaire, a measure of stigma that was validated and tested by USAID in Tanzania (Nyblade et al., 2005). Questions regarding stigma were also adapted from the Perceived HIV/AIDS Stigma Instrument for PLWHA, a 33-item instrument developed by Holzemer, et. al (2007) that measures six dimensions of HIV and AIDS-related stigma (verbal abuse, negative self-perception, healthcare neglect, social isolation, fear of contagion, and workplace stigma) experienced by PLWH. Participants were also asked to identify whether or not they believed that PLWH were stigmatized by the community, and where that stigma most likely stemmed from.

*Testing Location.* Participants were asked to identify the location that they would like to receive an HIV test in the future in order to assess whether geographic location of the testing site acts as a protective factor against experienced or felt stigma. Responses were coded to reflect locations that were near the participant, far from the participant, a non-governmental organization, or at a community testing event. Some participants identified they would prefer a home test. Participants who responded to more than three locations that were neither strictly close or strictly far away were considered to have varying opinions and were coded as having no preference.

*Attitudes towards HIV Testing.* HIV-testing attitudes were measured using a modified version of the HIV-Antibody Test Attitude Scale (HTAS), developed by Boshamer & Bruce (1999). This measure included 7 statements: two statements reflected

positive outcomes from testing, three assessed adverse outcomes, one reflected HIV testing avoidance, and one assessed concerns about confidentiality of the test. As such, the HTAS assesses attitudes towards testing as well as helps identify perceived barriers and benefits to obtaining an HIV-antibody test (Walker, 2004). Participants were asked to indicate whether they agreed or disagreed with the seven statements.

*Network Norm: Social Support & Disclosure.* Participants were asked how often they discuss HIV/AIDS and testing with other individuals in their community (4-point likert-scale ranging from ‘frequently’ to ‘never’) in order to better understand the social acceptance and conversation of the topic. Additionally, participants were asked to identify whether or not they knew someone who had ever been tested for HIV, and whether or not they knew someone who was currently living with HIV. Participants were also asked whether or not their family and friends would be supportive of their decision to get tested for HIV. To determine comfort with disclosure of an HIV status, participants were asked whether or not they would disclose their own HIV positive status to someone in their social network, who they would disclose to, and their perception of the general level of disclosure in their community.

*Future Interventions.* In order to better understand interventions related to the topic, participants were asked to write their recommendations for how interventions could better encourage more people to get tested for HIV. These qualitative responses were coded, grouped, and thematic themes were reported on.

**Data Analysis.** Quantitative survey questions were analyzed using SPSS 25 and descriptive statistics were reported. Correlations were used to explore the relationship

between whether or not someone had ever been tested and HIV knowledge, HIV-related stigma, and attitudes towards an HIV test. Analysis of the data can be found in the results section.

A thematic analysis approach was used to analyze the qualitative responses of the participants; the use of this approach implies that data were analyzed through examination and categorization of participants comments. This analysis was carried out in three phases: line-by-line coding of responses, examination and interpretation of the codes into descriptive themes, and the development of an overarching theme (Mhode & Nyamhanga, 2016).

**Protection of Human Subjects.** Permission to conduct the study was obtained from the Tanzanian government at the national level (the Committee on Science and Technology and the National Institute for Medical Research), the regional level (Arusha and Kilimanjaro Regional Secretaries), and the District level (District Medical Officers). In addition, permission for this research was obtained from the Institutional Review Board (IRB) at Arizona State University. Participants were also assured of confidentiality of information obtained. The study poses minimal risk to the participants.

## CHAPTER 4

### ANALYSIS OF RESULTS

**Participant Characteristics.** A total of 115 participants gave consent to participate in the study and completed a survey. Of those, 108 were available for analysis. Of participants in this study, 75 (69.4%) were men and 31 (28.7%) of them were women. The mean age of participants in years was 22.23 (SD = 2.167), and only 6.5% of all participants had ever been married at the time of the study. The mean reported household size was 5.0 (SD = 3.954). A majority of the participants in this study held a diploma (39.8%) or a bachelor's degree (25.9%), and 58.3% of participants attended public school throughout their education. Only 7.4% of participants stated that they were currently employed, and 79.6% identified their religion as Christianity, the most common religion in the Meru District area. Additional descriptive information can be found in Table 1.

**HIV Testing Behaviors.** Among the 108 participants included in the analysis (F=31, M=75), 76.9% (N=83) reported ever having been tested for HIV (see Table 1). Additionally, 83.3% of participants responded that they would get tested for HIV (either again or for the first time) within the next 12 months. Of the participants who stated that they had ever been tested (N=83), 72.3% of them had been tested within the previous 12 months. A majority of participants had been tested either one, two, or three times (24.1%, 18.1%, and 28.9% respectively), although there were 10 participants who indicated that they had been tested more than 5 times in the past for HIV. A majority of individuals stated that they received their most recent HIV test from a hospital (59.1%) or a dispensary (28.9%). Finally, of the individuals who had ever tested for HIV, 61.1% of



them indicated that they received some form of counseling either before or after getting their HIV test. See Table 2.

<b>Table 2. Responses related to previous HIV testing in participants who had ever been tested</b>			
		<b>Frequency</b>	<b>%</b>
<b>Tested Year</b>	2018	60	72.3
	2017	15	18.1
	2016	3	3.6
	2015	2	2.4
<b>Total Times Tested</b>	One	20	24.1
	Two	15	18.1
	Three	24	28.9
	Four	7	8.4
	More than Five	10	12.1
<b>Last Testing Location</b>	Hospital	49	59.1
	Dispensary	24	28.9
	Clinic	1	1.2
	Home	1	1.2
	Health Center	2	2.4
	NGO Event	2	2.4
	School	1	1.2
<b>Received Counseling</b>	Yes	66	61.1
	No	4	3.7

**Perceived Risk of HIV Infection.** The mean value of sexual partners for males in the last three months in this study was 1.10 (SD = 1.077) and for females was 0.62 (SD = .728). When combining both genders, most respondents stated that they were not likely to currently have HIV (83.3%) and that they were not likely to get HIV in the future (85.2%). When separating by gender, female participants were more likely to rank their

current and future risk of getting HIV as higher than males. When asked about their frequency of condom usage, a risk reduction behavior, 19.4% of females and 17.3% of males stated that they always use condoms when having sexual intercourse. The number of participants who indicated that they never used condoms was particularly high, 13.3% and 12.9% for males and females respectively.

**Table 3. Current and future perception of risk and engagement in risk reduction behaviors, separated by male and female**

		<b>%, Male</b>	<b>%, Female</b>
<b>Current Risk for HIV</b>	Not likely	81.3	87.1
	Somewhat likely	5.3	0
	Very likely	1.3	9.7
<b>Future Risk for HIV</b>	Not likely	81.3	93.5
	Somewhat likely	8	3.2
	Very likely	4	0
<b>Condom Frequency</b>	Never had sex	25.3	45.2
	Always	17.3	19.4
	Very Frequently	12	3.2
	Occasionally	5.3	12.9
	Rarely	9.3	0
	Very Rarely	8	0
	Never	13.3	12.9

**HIV Knowledge.** The mean overall score for correct answers on the knowledge measure (out of 9 possible correct responses) was 69.8% (SD = 16.4). This indicates that individuals in this study show a moderate-to-high level of knowledge about topics related to HIV/AIDS. However, there is clear evidence of misinformation in the context of this relatively high knowledge base. Items that were most frequently answered incorrectly

were “A person can get HIV by giving / donating blood” (66.3% by people who have ever been tested, and 64.0% by people who had never been tested), “Someone can prevent getting HIV by abstaining from sex” (38.6% and 40.0% for tested and not tested, respectively), and “People are likely to get HIV through deep kissing, or putting their tongue in their partner's mouth, if their partner is HIV positive” (28.9% and 44.0% for tested and not tested, respectively). Comparisons between individuals who had and had not been tested for HIV showed that the groups did not differ significantly on their overall scores, and there were no significant group differences on any of the individual knowledge items. Additionally, there were no significant correlations between an individual’s knowledge of HIV and their testing status.

**Table 4. Incorrect responses to AIDS knowledge questions among participants from Meru District who have and have not been tested for HIV.**

	Tested		Not Tested	
	n = 83		n = 25	
	No.	%	No.	%
People are likely to get HIV through deep kissing, or putting their tongue in their partner's mouth, if their partner is HIV positive (False)	24	28.9	11	44.0
There is a cure for AIDS (False)	8	9.6	1	4.0
The virus that causes AIDS can be transmitted from a mother to her baby during breastfeeding (True)	7	8.4	2	8.0
Someone can prevent getting HIV by abstaining from sex (True)	32	38.6	10	40.0
Someone can prevent getting HIV by remaining faithful to a faithful partner (True)	14	16.9	2	8.0
Someone can prevent getting HIV by always using condoms correctly (True)	11	13.3	7	28.0

In a married couple, it is possible for one person to have HIV and the other one not to have HIV (True)	5	6.0	5	20.0
A person can get HIV by giving/ donating blood (False)	55	66.3	16	64.0
It is possible to tell if someone has HIV just by looking at them (False)	10	12.0	3	12.0
**Correct responses are shown above in parentheses.				

As a way to understand how individuals learned about these topics, they were asked if and where they had ever received HIV prevention education in the past. A large number of participants (88.9%) identified that they had received some sort of HIV prevention education during primary school, secondary school, or college. Other participants shared that they received HIV prevention education from a non-governmental organization (6.5%). In addition, a majority of participants (60.2%) perceived that their community had only “some knowledge” about HIV/AIDS.

**Attitudes Towards HIV/AIDS.** Comparisons between HIV testing history groups on attitudes towards HIV/AIDS showed that both groups did not significantly differ on any of the measures to determine if individuals hold specific attitudes towards someone with HIV (Table 5). Despite the fact that there were no significant group differences between those who had and had not been tested, participants overall still expressed stigmatizing views towards HIV/AIDS. For example, 31.3% of individuals tested and 24.0% of individuals not tested responded that they agreed with the statement “I would feel ashamed if I was infected with HIV.” In addition, 62.7% of individuals tested and 72.0% of individual not tested agreed with the statement, “People living with

HIV are often abandoned by their spouse.” This indicates that individuals still hold views that reflect discrimination towards PLWH.

Surprisingly, many of the responses did not appear to reflect stigmatizing views. For example, only 3.6% of people tested and 8.0% of people not tested indicated that they agreed with the statement “HIV is a punishment from God.” In addition to the attitudes scale, 26.9% of participants identified that individuals who are living with HIV experience stigma from healthcare providers.

**Attitudes Towards HIV Antibody Tests.** Similarly to the measures for HIV stigma, responses towards an HIV antibody test were relatively positive. For example, 81.3% of people tested and 88.0% of people not tested stated that they agreed with the statement “HIV test information is kept very confidential by the medical staff doing the testing” and 83.1% of people tested and 76.0% of people not tested agreed with the statement “Anyone who is tested for HIV is smart.” Relatively low numbers of participants indicated that they were afraid that someone would find out about them getting an HIV test. Although none of the comparisons between an individual’s attitudes towards testing and their testing status were statistically significant, one of the measures came close: 36.0% of individuals who had never been tested said that they agreed with the statement, “I would rather not know if I have HIV” compared to 18.1% of individuals who had been tested in the past ( $p=0.057$ ,  $OR = 2.60$ ,  $95\% CI = 0.957, 7.061$ ).

Comparisons between HIV testing history groups on attitudes towards HIV-antibody tests showed that both groups did not significantly differ on any of the measures.

**Table 5. HIV testing attitudes and HIV/AIDS-related stigmatizing attitudes among participants in Meru District who have and have not ever been tested for HIV.**

	Tested		Not Tested		OR *	95% CI Lower	95% CI Upper
	n = 83		n = 25				
	No.	%	No.	%			
<b>HIV Stigmas/ Attitudes</b>							
People with HIV/AIDS should be ashamed of themselves.	8	9.6	2	8.0	0.804	0.159	4.059
I would feel ashamed if I was infected with HIV.	26	31.3	6	24.0	0.680	0.243	1.903
People with HIV/AIDS are dirty.	1	1.2	0	0.0			
I would play sports with someone who has AIDS	79	94.0	22	88.0	0.376	0.078	1.808
HIV is a punishment from God.	3	3.6	2	8.0	2.290	0.361	14.540
I do not want to be friends with someone who has AIDS.	5	6.0	2	8.0	1.418	0.257	7.815
People living with HIV are often excluded from social gatherings.	30	36.1	12	48.0	1.700	0.679	4.259
People living with HIV are often abandoned by their spouse.	52	62.7	18	72.0	1.731	0.619	4.835
<b>HIV Testing Attitudes</b>							
HIV test information is kept very confidential by the medical staff doing the testing	69	83.1	22	88.0	1.382	0.36	5.298
It would be embarrassing to get tested for HIV	10	12.0	4	16.0	1.212	0.349	4.205
People in my life would leave me if I had HIV	19	22.9	7	28.0	1.365	0.493	3.782
I am afraid someone would find out I was tested for HIV	19	22.9	4	16.0	0.642	0.195	2.112

I would rather not know if I have HIV	15	18.1	9	36.0	2.600	0.957	7.061
Anyone who is tested for HIV is smart	69	83.1	19	76.0	0.716	0.227	2.260
Getting tested for HIV helps people from getting HIV.	52	62.7	14	56.0	0.781	0.308	1.979
OR* = odds ratios for comparison of people tested for HIV to people not tested							

**Social Networks.** A majority of participants in the study indicated that they occasionally discussed HIV/AIDS with other people in their community (35.2%). Some individuals frequently (23.1%) discussed HIV, while others rarely discussed the topic (28.7%). These frequencies were similarly reported for whether or not participants talked about HIV testing in their community. In addition, 40% of individuals who had never tested for HIV indicated that they knew someone who was HIV positive, while 57.8% of individuals who had ever tested identified that they knew someone who was HIV positive. Similarly, 60% of people who had never tested identified that they knew someone who had tested previously, compared to 85.5% of individuals who had ever tested. Correlations between getting an HIV test and knowing someone who had either tested were significant ( $p = 0.003$ ). In addition, discussing HIV tested within one's social group was also positively correlated with getting an HIV test ( $p = 0.017$ )

**Desired Testing Locations.** Respondents were asked to indicate from a list of choices their desired location for a test. About half of respondents chose a location that was considered to be far away from their home location (>20kms) (44.4%), while a smaller number indicated that they would prefer to go to a location that was close to their home (<5kms) (27.8%). A total of 10 participants responded that they would prefer to

take a home test for HIV instead of traveling to a health facility (9.3%). See Table 6 for more information.

<b>Table 6. Frequency of desired testing location, listed from highest to lowest</b>		
	<b>Frequency</b>	<b>%</b>
Far from me	48	44.4
Close to me	30	27.8
Home Test	10	9.3
No preference	9	8.3
Testing Event	5	4.6
NGO	4	3.7

**Community Barriers to Seeking an HIV Test.** Themes related to the barriers for seeking or receiving an HIV test emerged out of a thematic analysis process of responses. In this process, responses were given a code, and then those codes were grouped into the following global themes: fear, stigma, discrimination, social capital, infrastructure, education, and internal motivation (see Table 7). Each participant was asked to give three responses to this question. Out of 108 participants (a total of 324 responses), 46 responses were not provided, and were therefore excluded from the frequency calculations. The major themes are described in depth below.

<b>Table 7: Global themes and codes for barriers related to getting an HIV test, from highest to lowest frequency.</b>			
<b>Theme</b>	<b>Code</b>	<b>Frequency</b>	<b>%</b>
<b>Education</b>		<b>87</b>	<b>31.29%</b>
	Lack of/ insufficient education	61	21.94%
	Bad beliefs or misconceptions	26	9.35%



<b>Fear</b>		<b>71</b>	<b>25.54%</b>
	Fear of outcome	32	11.51%
	Fear of sickness/ death	5	1.80%
	Fear (not identified)	28	10.07%
	Fear as a result of risky behavior	6	2.16%
<b>Stigma</b>		<b>59</b>	<b>21.22%</b>
	Stigma (external/ felt stigma from community)	28	10.07%
	Confidence/ self-doubt (internal stigma)	31	11.15%
<b>Infrastructure</b>		<b>20</b>	<b>7.19%</b>
	No tools	2	0.72%
	No services/ providers	14	5.04%
	No trust/ confidentiality	4	1.44%
<b>Discrimination</b>		<b>18</b>	<b>6.47%</b>
	Fear of segregation/ isolation	18	6.47%
<b>Internal Motivation</b>		<b>17</b>	<b>6.12%</b>
	No time	3	1.08%
	No motivation	4	1.44%
	Not suffering	10	3.60%
<b>Social Capital</b>		<b>6</b>	<b>2.16%</b>
	No support	6	2.16%

*Education.* The most common theme that emerged as a barrier to not getting tested for HIV was education (31.29%). In particular, responses described a complete lack of education or knowledge regarding how HIV is transmitted and the importance of

knowing one's status through an HIV test. Responses also described an insufficient amount of education provided to the community, which could indicate that although there is education, individuals are not getting all of the correct information that they need. Finally, 9.35% of the responses described how community members hold misconceptions or 'bad beliefs' about HIV/AIDS, which impact their willingness to get a test.

“Bad beliefs concerning the transmission of HIV among the community members” (male, 23)

“There is no adequate education to make people aware of the importance of making body checkup or getting an HIV test” (male, 24)

“An awareness is not present to most of the members of communities about the advantages of testing HIV” (male, 25)

*Fear.* Responses that indicated fears were the next most common cited barriers to seeking an HIV test (25.54%). This theme contained a number of codes, including fear of the outcome or result of the test, fear of being sick or of dying as a result of being HIV positive, fear stemming from engagement in risky behavior, and a generalized fear that was not identified as any of the above.

“People who don't know their status are having sex with others who don't know their status and they are not using protection” (male, 23)

“Fear, two things rising on the head of people that if he or she affected or not after test what will happen and that this becomes difficult to find a solution or the best answer.” (male, 22)

“Fear among many youth because they engage themselves in sexual intercourse with many women” (male)

“People from my community have the perception that when you find infected the difficult life will start over there, so they are afraid” (male, 24)

Stigma. The theme of stigma included two major types of responses: those that indicated a fear of external or received stigma from someone in the community, and those that indicated self-doubt, shame, or a lack of confidence (grouped here as internal stigma). Internal stigma responses were cited more frequently than external fear (11.15% and 10.07% respectively), however both reflect major barriers to accessing HIV testing services.

“Negative thoughts that if you get tested for HIV, then you are involved in bad behavior” (male, 20)

“The view of people in the community that if they get tested and they found out they are positive, their community will discriminate against them” (male, 19)

“The fear and worry that if people find out they are HIV positive, how will they live with their communities” (male, 22)

Infrastructure. Responses that indicated that there is a lack of equipment or tools to perform accurate testing or a lack of service providers to conduct testing in the areas where participants live constituted 7.19% of all responses. In addition, a small number of responses (1.44%) indicated that a barrier to seeking an HIV test is the perception that there is a lack of confidentiality among healthcare workers. This was grouped here

because it is seen as a breakdown in the provision of confidential testing services and locations.

“Inadequate doctors with professionals in our community to give on the general counseling about HIV” (male, 24)

“I am not sure if my secret may be secured” (male, 24)

“The government doesn't prioritize the lack of medical equipment” (male, 24)

*Discrimination.* This theme includes responses that indicated individuals are not seeking an HIV test because they are afraid of being isolated or segregated by their community (6.47%). In these responses, individuals showed that they are particularly concerned about what might happen in regard to their social standing if they receive a positive HIV diagnosis.

“Many people are afraid of getting tested for HIV because they do not believe in themselves, and they are also afraid to get tested because if they are positive, they will be segregated against” (male, 20)

*Internal Motivation.* This theme reflected codes that show an individual's internal thought process that pose a barrier for seeking an HIV test, including not having any time to get tested (1.08%), not feeling signs of being sick or suffering (3.60%), and not feeling any motivation (1.44%). That absence of motivation in this case is related to the thought that the individual doesn't feel any concern about being positive, and therefore does not feel that getting an HIV test is necessary.

“HIV/AIDS is nowadays subjected as normal disease, so people think that it is not important to test their health” (male, 22)

“Frequent testing is maybe only necessary for those who have frequent sex/ engage in risky behaviors” (male, 30)

“Busy/poverty, many people however their poor in my community in such a way they don't have time to test their blood” (male, 24)

*Social Capital.* An individual’s social network and their perception of a lack of support to get an HIV test from other individuals within that network, proved to be a minor barrier to accessing HIV testing services (2.16%).

“I am waiting for support from my spouse” (female, 26)

**Motivations for Testing or Not Testing.** Themes related to an individual’s personal motivations for getting an HIV test or for not getting an HIV test emerged out of a thematic analysis process of responses provided.

*Motivations for Testing.* Participants who had ever been tested (n=83, 76.9%) provided their motivations for seeking an HIV test, and responses were grouped (see Table 8). Each participant was asked to provide three motivations or reasons for getting tested. Out of 83 participants (a total of 249 possible responses), 63 responses were not provided, and were therefore excluded from the frequency calculations.

The most reported reason for getting an HIV test of those who had ever been tested was that the individual had a desire to know their health status (52.15%). Generally, knowing one's health status can ensure that they are aware of their own health and can take appropriate action when necessary. This is indicative of preventative health seeking behaviors. Another significant motivation for seeking an HIV test is the desire to protect oneself or others, particularly sexual partners, from transmitting HIV (19.35%). Moderate motivations for seeking an HIV test were that the individual had received education about the importance of a test and therefore felt it necessary to check their HIV status (8.06%), that the individual was receiving another health checkup or donating blood and was offered an HIV test (6.45%), and that the individual wanted to encourage others in their social group to get an HIV test (4.30%). Less common motivations for seeking an HIV test were that the individual had engaged in risky behavior (2.69%), that the individual felt strongly supported by their social network (2.69%), that the individual wanted to prove to their partner that they were HIV negative (1.61%) or they felt distrust of their partner (1.61%), and that they felt sick (1.08%).

“To influence others to test HIV/AIDS” (male, 26)

“An anxiety from my partner on her health condition” (male, 23)

“To get confidence in the safety of my health status” (female, 23)

“To start practicing safe sex with my partner” (female, 28)

Reasons for Not Testing. Participants who had never been tested (n=25, 23.1%) provided their reasons for not seeking or receiving an HIV test, and responses were grouped (see Table 8). Each participant was asked to provide three reasons they had

never sought an HIV test. Out of 25 participants who had never been tested (a total of 75 possible responses), 3 responses were not provided, and were therefore excluded from the frequency calculations.

The most commonly cited reason for not seeking an HIV test was that the individual felt no concern about having HIV because they were either not engaging in risky behavior, not sexually active, or not sick (27.78%). The second most common reason for not getting an HIV test was that the participant had fear or anxiety about the test, including both the result and the process of getting tested (19.44%). Individuals also indicated that a reason for not getting tested was because they didn't feel like they had enough information about HIV, that they had never received any education about the topic, or that they were not aware of the importance of testing for HIV (16.67%). Of all responses, 6 of them indicated that there was no external incentive to get tested, either from educators or healthcare providers (8.33%), 6 of them indicated that there were no HIV testing services in their location (8.33%), and 6 of them indicated that the participant was underage at the time testing was offered (8.33%). Reasons for getting tested that were less cited included that they didn't feel as though they had any external support from their friends or family (4.17%), that getting an HIV test was time consuming (4.17%), and that they had a lack of courage that would motivate them to test for HIV (2.78%).

“Because I have never had a fever and I have never suffered from any of the opportunistic illnesses” (female, 21)

“Shortage of the center or institution in my community that emphasize people to test for HIV” (male, 22)

“Being confident in my past use of condoms every time I have sex with my partner” (male, 22)

“I am afraid that if I get tested and I am positive, what will happen next” (male, 30)

**Table 8: Motivations/ reasons for testing and not testing for HIV, from highest to lowest frequencies.**

<b>Reasons for Testing</b>	<b>Frequency</b>	<b>%</b>
Know my health status	97	52.15%
Protect myself/ others	36	19.35%
Received education	15	8.06%
Alternative checkup/ procedure	12	6.45%
Encourage others	8	4.30%
Risky behavior	5	2.69%
External support	5	2.69%
Proof to partner	3	1.61%
Distrust in partner	3	1.61%
Felt sick/ sick signs	2	1.08%
<b>Reasons for not testing</b>	<b>Frequency</b>	<b>%</b>
No concern (no sexual intercourse/ not sick)	20	27.78%
Fear/anxiety (incl. fear of needles)	14	19.44%
Lack of education/ awareness	12	16.67%
No external incentive	6	8.33%
No services	6	8.33%
Underage	6	8.33%
No external support	3	4.17%



Time consuming	3	4.17%
Lack of courage	2	2.78%

**Suggested Interventions.** Themes related to suggested interventions for improving testing uptake in the community emerged out of a thematic analysis process. In this process, responses were given a code, and those codes were then grouped into the following global themes: provision of education, improvement of infrastructure, and social capital (see Table 9). Out of 108 total possible responses to this question, 11 responses were left blank, and were therefore excluded from the frequency calculations.

Education. The most common intervention that was offered by participants in the study was the provision of education (88.66%), however there were varying results for both what should specifically be focused on in HIV education interventions and how they should be delivered. The most common topic that was suggested for education programs was the importance and benefits of receiving an HIV test (26.08%), followed by a focus for the education program on the importance of protecting oneself or protecting others (24.74%) and that getting an HIV test is generally important for overall health (11.34%). There were a few responses (n=3, 3.09%) that focused specifically on reducing negative misconceptions or ‘bad beliefs’ held by community members that could be preventing individuals from getting an HIV test. Of the methods that were suggested for offering HIV prevention education, 11.34% of responses indicated that education should be given through seminars and workshops in the community, 3.09% indicated that education should be given through social media or text messaging services, and 2.06% indicated that education should be peer-to-peer. Finally, 6.19% of responses indicated that

education should include topics of empowerment as a way to show people that they can still achieve their life goals even if they test positive for HIV.

“Through telling them the importance of doing a test for HIV, that someone should avoid things which can lead him/her to become infected like having love affairs with other people because they could be already affected [with HIV]”  
(male, 26)

“Educating them on the importance of testing, giving them information on the number of infections/ statistics, and convincing them to believe in themselves and not being scared” (male, 21)

“By telling them about the effects of HIV/AIDS and the importance of testing through various seminars and films that can convince them to test for HIV”  
(female, 19)

“Educating them about the benefits of testing for HIV/ AIDS with regards to their health, creating a climate of self-belief and a belief that having HIV/AIDS is not the end of life” (male, 22)

“Showing the importance of testing for HIV, encouraging people and instilling bravery in them to know that having HIV is not the end of your life, being faithful and avoiding unprotected sex so that later on you will be brave enough and won't have a fear of getting tested” (male, 23)

*Infrastructure.* Improvement of infrastructure was provided as another important strategy for increasing testing behaviors in the community (8.25%). Specifically, participants suggested that the provision of services at locations in rural areas or closer to where community members reside, as well increasing confidentiality at these locations, could improve testing uptake.

“I would educate the community to go to the hospital or any health service to test for HIV/AIDS, and professionals of testing HIV/AIDS must go to any area to invite people to test for HIV” (male)

“Giving them tools to test for HIV in their homes or their communities where they live, for example in their houses and in nearby dispensaries” (male, 22)

*Social Capital.* A small number of responses (n=3, 3.09%) indicated that increasing support for PLWH would be a good strategy for encouraging testing, since community members would see that they have access to adequate care and social support.

“Give education about HIV/AIDS to the whole community, improve services to those with HIV/AIDS by creating groups of people who are infected so that they can talk about things that affect them” (male, 19)

<b>Table 9: Suggested interventions for improving testing uptake in the community, ranked from highest to lowest frequency.</b>			
<b>Global Theme</b>	<b>Specific Intervention</b>	<b>Frequency</b>	<b>%</b>
<b>Provision of Education</b>		<b>86</b>	<b>88.66%</b>
	Important for Overall Health	11	11.34%

	Importance/ Benefits of Testing	26	26.80%
	Protecting Oneself or Others	24	24.74%
	Through Seminars & Workshops	11	11.34%
	Through the Media	3	3.09%
	Empowerment	6	6.19%
	Peer Education	2	2.06%
	Discouraging Bad Beliefs/ Reducing Stigma	3	3.09%
<b>Improvement of Infrastructure</b>		<b>8</b>	<b>8.25%</b>
	Confidentiality at Service Locations	1	1.03%
	Provision of Services	7	7.22%
<b>Social Capital</b>		<b>3</b>	<b>3.09%</b>
	Supporting PLWH	3	3.09%

## CHAPTER 5

### DISCUSSION & FUTURE RECOMMENDATIONS

**Discussion.** Previous research has shown clear connections between HIV-related stigma and discrimination and its impact on HIV testing, accessing antiretrovirals, and adhering to HIV medication. Stigma and discrimination also greatly impact issues of disclosure and motivation to seek care, as well as can affect interpersonal relationships and psychosocial outcomes. This research was intended to better understand HIV testing behaviors in Northern Tanzania, as well as better understand the impact of HIV-related stigma and attitudes towards testing on an individual's willingness to get an HIV test.

Many of the participants in this study had previously been tested for HIV - a percentage higher than the national average for individuals who have been tested and know their HIV status. This could be as a result of the sociodemographics of the group surveyed, and could show that young people specifically are seeking HIV tests in higher numbers than the rest of the population. In addition, this could be related to the fact that many of the individuals who were surveyed had access to higher education, and therefore had higher knowledge of HIV/AIDS, as well as better access to healthcare services. It might be important to understand the relationships and dynamics of young people in order to inform interventions and solutions that would work for the entire community.

The results around social networks and disclosure from this study are particularly interesting. They show that getting an HIV test and knowing someone who has previously received an HIV test are significantly and positively correlated. In addition, significant correlations existed between getting an HIV test and talking about HIV to others in the community. These results indicate that facilitating discussions about

HIV/AIDS among community members, as well as encouraging individuals to share when they have received an HIV test, are two strategies through which interventions could improve testing uptake. It is likely that stigma is reduced slightly just by the simple act of talking about taboo issues, which allows more individuals to feel confident in their health decisions. In order to organically create these open dialogues within a community and improve testing uptake, social groups could be established, or a trusted “peer leader” could be identified and trained to facilitate discussions.

Another interesting finding from this research is related to the attitudes that participants held about HIV/AIDS. Of the individuals who had ever been tested, about one-third indicated that they would feel ashamed if they were infected with HIV. Only about one-fourth of individuals who had never been tested indicated this concern. This shows that individuals who had been tested were more likely to associate shame with being HIV positive. Although shame is typically seen as a barrier for engaging in a health seeking behavior, it could in this case serve as a motivator to get tested. There is more research to be complete in order to better understand this phenomenon.

The barriers identified by individuals as hindering access to, or seeking of, HIV testing are important to note. The major themes in this regard were education, fear (of the outcome, of being sick, etc.), and stigma. Even though respondents in the survey did not seem to have overwhelmingly stigmatizing attitudes about HIV, they still perceive this as a major barrier. This could indicate that our research did not fully capture the attitudes held by the entire community about HIV/AIDS and shows the importance for interventions that target stigma and fear through inclusive education. UNAIDS and the World Health Organization cite that fear of stigma and discrimination are the main reason

why people are reluctant to get tested, which is in line with our findings (WHO, 2011). In addition, Thapa et al. (2017) found that stigma-reduction mechanisms are often influenced by an interaction of various social-contextual and individual factors, and that by reducing HIV-related stigma, the uptake of HIV testing can be increased.

With these results, more effective and powerful interventions will be developed, ones that are rooted in behavior-change and take into account evolutionary psychology, to increase the number of individuals who know their HIV status. We are fighting for an AIDS-free generation, and this research allows for a better achievement of national and international goals to be successful. The partnership created to conduct this research contributes to the impact by creating an international collaboration to elevate our understanding of the issue and to develop strategies to reduce the impact of stigma and affect attitudinal change about HIV/AIDS in a global context.

**Limitations.** Since HIV-related stigma and discrimination are still widely experienced, responses to questions on the surveys could have been negatively impacted. Additionally, sexual health topics are incredibly taboo and are often not discussed among the general public. This could mean that participants did not answer questions in an accurate way and could have skewed their responses in order to “look good” (i.e. not show that they hold stigmatizing views). To overcome these pitfalls, it was important to work closely with local hospital facilities, community leaders, and universities, and each participant was encouraged to answer questions honestly and accurately.

**Recommendations for Future Interventions.** Future recommendations for both research and intervention development as gleaned through this research are as follows.

### Research:

- In order to successfully achieve the 90-90-90 goals, more research should follow this that helps to better define the stigma and discrimination related challenges to accessing HIV testing services.
- Design research studies that are based on principles of psychology and evolution to better understand why individuals with HIV are stigmatized, as well as how we might be able to utilize stigma as a motivator for getting an HIV test.
- Expand the scope and geographic region of this study in order to better understand how these findings generalize to the entire country.
- Conduct research to better understand the effect of social networks (relationships and friendships) on willingness to get tested. Peer-education programs could also be looked at here, to see if they increase willingness to test.
- Additional research is needed to more deeply understand barriers for accessing HIV testing in the community. In-depth interviews would be very useful here.

### Interventions:

- In addition to focusing on knowledge increase in HIV-prevention education programs, there is a need for organization and schools to include stigma and discrimination in their conversations or lessons. This allows students to be able to see for themselves the effects that stigma have on their own lives, as well as how they are contributing to it. They get to discuss together how to make a difference and empower others to get tested.



- A shift from knowledge based-education to behavior-change education is needed. By focusing on behavior change, participants have an opportunity to look at what is important in their lives and better understand their motivations for getting an HIV test. They also have an opportunity to discuss, and ask questions about, things that they are fearful of.
- Based on current and future literature, design interventions (education programs, marketing campaigns, etc.) that make getting tested for HIV the “norm” (utilize stigma to encourage positive behavior).
- HIV prevention education programs should be coupled with on-site testing as often as possible.

**Alignment with the United Nations Sustainable Development Goals.** The understanding of HIV stigma as it related to HIV testing relates to a number of sustainable development goals:

- Goal 3. Ensure healthy lives and promote well-being for all at all ages
  - Our research most aligns with this SDG. In order to achieve national and international development goals, it is important to better understand what inhibits health-seeking behaviors and what promotes them. In regard to infectious diseases that have a high prevalence rate in the study area, the health of all members of the community is at risk if these areas are not addressed.
- Goal 5. Achieve gender equality and empower all women and girls

- It is interesting to see how sexual and reproductive health strategies vary based on the gender of the individual. In Tanzania, men have a lower chance of knowing their HIV status and they are less likely to get tested. As a result, HIV prevalence rates continue to be high.
- Goal 16. Promote peaceful and inclusive societies for sustainable development, provide access to justice for all and build effective, accountable and inclusive institutions at all levels.
  - One of the goals of this research is to better understand HIV-related stigma at the community level so that effective interventions can be developed to reduce stigma. Only with the reduction of stigma and discrimination against health-related issues can an inclusive environment be created for all.
- Goal 17. Strengthen the means of implementation and revitalize the global partnership for sustainable development.
  - In conducting this research, multiple health stakeholders were connected, and open, constructive collaboration on HIV related issues were encouraged.

## REFERENCES

- AIDSInfo (2018). HIV Medication Adherence. Retrieved from: <https://aidsinfo.nih.gov/understanding-hiv-aids/fact-sheets/21/54/hiv-medication-adherence>
- Amuri, M., Mitchell, S., Cockcroft, A., & Andersson, N. (2011). Socio-economic status and HIV/AIDS stigma in Tanzania. *AIDS Care*, 23(3), 378-382.
- Berger, B., Ferrans, C., & Lashley, F. (2001). Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale. *Research in Nursing & Health*, 24(6), 518-529.
- Chidrawi, C., Greeff, M., Temane, M., & Doak, C. (2016). HIV stigma experiences and stigmatisation before and after an intervention. *Health SA Gesondheid: Journal of Interdisciplinary Health Sciences*. 21, 196-205. DOI: 10.1016/j.hsag.2015.11.006.
- Centers for Disease Control and Prevention (CDC), ICAP, Columbia University Mailman School of Public Health, Ministry of Health (Zanzibar), Ministry of Health, Community Development, Gender, Elderly and Children (MoHCDEC) (Tanzania), National AIDS Control Program (NACP) (Tanzania), National Bureau of Statistics (Tanzania), National Health Laboratory Quality Assurance and Training Centre (NHLQATC) (Tanzania), Office of Chief Government Statistician (OCGS-Zanzibar), Tanzania Commission for AIDS (TACAIDS), Zanzibar AIDS Commission (ZAC). Tanzania HIV Impact Survey 2016-2017.
- Department of Policy and Planning (2013). List of HIV Care and Treatment Centers (CTC). Ministry of Health and Social Welfare, Government Open Data Portal. <http://opendata.go.tz/dataset/list-of-hiv-care-and-treatment-centre-ctc-by-district>
- Fakultet, P., & Lorentzen, K.R. (2003). The Enigma of HIV/AIDS-related Stigma. A theoretical exploration of HIV/AIDS-related stigma in Sub Saharan Africa.
- Gamell, A., Letang, E., Jullu, B., Mwaigomole, G., Nyamtema, A., Hatz, C., . . . Tanner, M. (2013). Uptake of guidelines on prevention of mother-to-child transmission of HIV in rural Tanzania: Time for change. *Swiss Medical Weekly*, 143, W13775.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Prentice Hall; Englewood Cliffs, NJ
- Handbook for Curriculum Planners (1994). School health education to prevent AIDS and STDs. World Health Organization and United Nations Educational, Scientific, and Cultural Organization.

Holzemer, W., Uys, L., Chirwa, M., Greeff, M., Makoae, L., Kohi, T., . . . Durrheim, K. (2007). Validation of the HIV/AIDS Stigma Instrument—PLWA (HASI-P). *AIDS Care*, 19(8), 1002-1012.

Holzemer, W., Uys, L., Makoae, L., Stewart, A., Phetlhu, R., Dlamini, P., . . . Naidoo, J. (2007). A conceptual model of HIV/AIDS stigma from five African countries. *Journal of Advanced Nursing*, 58(6), 541-551.

International Labour Organization (ILO) (2018). Tanzania launches a campaign for HIV testing countrywide in Dodoma. Retrieved from: [https://www.ilo.org/addisababa/media-centre/pr/WCMS\\_632906/lang--en/index.htm](https://www.ilo.org/addisababa/media-centre/pr/WCMS_632906/lang--en/index.htm)

Kabiru, C., Beguy, D., Crichton, J., & Zulu, E. (2011). HIV/AIDS among youth in urban informal (slum) settlements in Kenya: What are the correlates of and motivations for HIV testing? *BMC Public Health*, 11(1), 685.

Kalichman, S., & Simbayi, L. (2003). HIV testing attitudes, AIDS stigma, and voluntary HIV counselling and testing in a black township in Cape Town, South Africa. *Sexually Transmitted Infections*, 79(6), 442-447.

Koku, E. (2011). Desire for, and Uptake of HIV Tests by Ghanaian Women: The Relevance of Community Level Stigma. *Journal of Community Health*, 36(2), 289-299.

Lorentzen K, Morris S. (2003). The Enigma of HIV/AIDS-related Stigma. A theoretical exploration of HIV/AIDS-related stigma in Sub Saharan Africa.

Lyimo, R., Stutterheim, S., Hospers, H., De Glee, T., Van Der Ven, A., & De Bruin, M. (2014). Stigma, Disclosure, Coping, and Medication Adherence Among People Living with HIV/AIDS in Northern Tanzania. *AIDS Patient Care and STDs*, 28(2), 98-105.

Makoae, L.N., Greeff, M., Phetlhu, R.D., Uys, L.R., Naidoo, J.R., Kohi, T.W., Dlamini, P.S., Chirwa, M.L., & Holzemer, W.L. (2008). Coping with HIV-related stigma in five African countries. *Journal of the Association of Nurses in AIDS Care*, 19(2), 137-146. Doi: 10.1016/j/jana/2007.11.004

Mhode, M. & Nyamhanga, T. (2016). Experiences and impact of stigma and discrimination among people on antiretroviral therapy in Dar es Salaam: a qualitative perspective. *AIDS Research and Treatment*. Doi: 10.1155/2016/7925052

Mwangome, Mary N., Geubbels, Eveline, Wringe, Alison, Todd, Jim, Klatser, Paul, Dieleman, Marjolein, & KIT: Biomedical Research. (2017). A qualitative study of the determinants of HIV guidelines implementation in two south-eastern districts of Tanzania. *Health Policy and Planning*, 32(6), 825-834.  
NACP (2008). Factors influencing ART adherence: qualitative findings from selected sites in Tanzania. National AIDS Control Programme.

NACP (2012). National guidelines for the management of HIV and AIDs, 4th edition. Ministry of Health, Community Development, Gender, and Children. National AIDS Control Programme.

NACP (2013). Third Health Sector HIV and AIDS Strategic Plan (HSHSP III) 2013 – 2017. Ministry of Health, Community Development, Gender, and Children. National AIDS Control Programme.

NACP (2017). Health Sector HIV and AIDS Strategic Plan 2017-2022 (HSHSP IV). Ministry of Health, Community Development, Gender, and Children. National AIDS Control Programme.

National Bureau of Statistics (NBS) [Tanzania] and ORC Macro (2005). Tanzania Demographic and Health Survey 2004-05. Dar es Salaam, Tanzania: National Bureau of Statistics and ORC Macro.

Newman, P., Grusky, O., Roberts, S., & Rivkin, I. (2002). Organizational factors in the early detection of HIV. The XIV International AIDS Conference.

Nsimba, S., Irunde, H., & Comoro, C. (2010). Barriers to ARV Adherence among HIV/AIDS Positive Persons taking Anti-Retroviral Therapy in Two Tanzanian Regions 8-12 Months after Program Initiation. *J AIDS Clinic Res* 1:111. Doi:10.4172/2155-6113.1000111

Nyblade, et al. (2005). Working Report Measuring HIV Stigma: Results of a Field Test in Tanzania. USAID.

Nyblade, L. & MacQuarrie, K. (2006). Can we measure HIV stigma and discrimination? Current knowledge about quantifying stigma in developing countries. USAID.

Pitpitan, E., Kalichman, V., Eaton, S., Cain, C., Sikkema, L., Skinner, A., . . . Pieterse, K. (2012). AIDS-Related Stigma, HIV Testing, and Transmission Risk Among Patrons of Informal Drinking Places in Cape Town, South Africa. *Annals of Behavioral Medicine*, 43(3), 362-371.

Prime Minister's Office United Republic of Tanzania. (2013). Summary and Analysis of the Comprehensive Council Health Plans 2013/2014. Dar es Salaam.

Rabkin, M., El-Sadr, W., Abrahams, E. (2003) MTCT-Plus Clinical Manual. Mailman School of Public Health Columbia University.

Rao, D., Kekwaletswe, T., Hosek, S., Martinez, J., Rodriguez, F., (2007). Stigma and social barriers to medication adherence with urban youth living with HIV. *AIDS Care* 19(1):28–33.

Orrell, C., Semvua, H., Bartlett, J., & Boulle, A. (2017). Predictors of non-adherence to antiretroviral therapy among HIV infected patients in northern Tanzania. *PLoS One*, 12(12), E0189460.

Semvua SK, Orrell C, Mmbaga BT, Semvua HH, Bartlett JA, Boulle AA (2017) Predictors of non-adherence to antiretroviral therapy among HIV infected patients in northern Tanzania. *PLoS ONE* 12(12): e0189460.

Smoot, D., & Garbanati, James. (2002). Differences in HIV Testing Attitudes, Decision Certainty and Coping Style between Testers and Nontesters for the HIV Antibody, ProQuest Dissertations and Theses.

Souteyrand, Y., Collard, V., Moatti, J., Grubb, I., & Guerma, T. (2008). Free care at the point of service delivery: A key component for reaching universal access to HIV/AIDS treatment in developing countries. *Aids*, 22(S1), S161-S168.

TACAIDS et al. (2013). Tanzania HIV/AIDS and Malaria Indicator Survey 2011-12. Dar es Salaam.

TACAIDS. (2014). National HIV and AIDS response report 2013, Tanzania mainland. Dar es Salaam.

TACAIDS (2016). Care and treatment programme. Retrieved from: [http://www.tac aids.go.tz/index.php?option=com\\_content&view=category&layout=blog&id=446&Itemid=4230](http://www.tac aids.go.tz/index.php?option=com_content&view=category&layout=blog&id=446&Itemid=4230)

Tanzania Commission for AIDS (TACAIDS), Zanzibar AIDS Commission (ZAC), National Bureau of Statistics (NBS), Office of the Chief Government Statistician (OCGS), and ICF International. (2013). Tanzania HIV/AIDS and Malaria Indicator Survey 2011-12. Dar es Salaam, Tanzania: TACAIDS, ZAC, NBS, OCGS, and ICF International.

Thapa, S., Hannes, K., Cargo, M., Buve, A., Aro, A., & Mathei, C. (2017). Building a Conceptual Framework to Study the Effect of HIV Stigma-Reduction Intervention Strategies on HIV Test Uptake: A Scoping Review. *Journal of the Association of Nurses in AIDS Care*, 28(4), 545-560.

Traube, D. E., Holloway, I. W., & Smith, L. (2011). Theory development for HIV behavioral health: empirical validation of behavior health models specific to HIV risk. *AIDS care*, 23(6), 663-70.

@umwalimu (2018). Twitter. <https://twitter.com/umwalimu>

UNAIDS. (2011). Getting to zero: 2011-2015 strategy. Retrieved from: <http://>

[www.unaids.org/sites/default/files/sub\\_landing/files/JC2034\\_UNAIDS\\_Strategy\\_en.pdf](http://www.unaids.org/sites/default/files/sub_landing/files/JC2034_UNAIDS_Strategy_en.pdf).

UNAIDS (2014). 90-90-90 - an ambitious treatment target to help end the AIDS epidemic. Retrieved from: <http://www.unaids.org/en/resources/documents/2017/90-90-90>

UNAIDS (2016). United Republic of Tanzania HIV and AIDS Estimates. Retrieved from: <http://www.unaids.org/en/regionscountries/countries/unitedrepublicoftanzania>

UNAIDS (2018). Fact Sheet - World AIDS Day 2017. Retrieved from: <http://www.unaids.org/en/resources/fact-sheet>

USAID (2015). Strengthening Health Systems to Support HIV and AIDS Prevention Care and Treatment. Retrieved from: <https://www.usaid.gov/what-we-do/global-health/hiv-and-aids/technical-areas/strengthening-health-systems-support-hiv>

US Embassy Dar es Salaam (2018). United States Renews its Commitment to Combat HIV/AIDS in Tanzania. Retrieved from: <https://tz.usembassy.gov/united-states-renews-its-commitment-to-combat-hiv-aids-in-tanzania/>

Walker, L. (2004). Components of the health belief model and HIV testing decisions. University of North Carolina at Wilmington. Dissertation.

Weiss, M., & Ramakrishna, J. (2001). Conference examines need for more study of AIDS stigma. *AIDS Policy Law* 16(18):4.

World Health Organisation (WHO) (2011). Global HIV/AIDS Response: Epidemic update and health sector progress towards Universal Access: Progress Report 2011

Yi, S., Chhoun, P., Pal, K., Chhim, K., Ngin, C., & Brody, C. (2018). Sexual behaviors, HIV knowledge, HIV testing attitudes and recent HIV testing among female entertainment workers in Cambodia: A cross-sectional study. *PLoS One*, 13(7), E0198095.

APPENDIX A  
SURVEY QUESTIONNAIRE, ENGLISH



**SECTION ONE - DEMOGRAPHIC INFORMATION**

What is your gender? (Circle One Answer)	MALE	FEMALE
What is your age?		
Where were you born? (City and Country)		
Where do you live now?		
What is your tribe?		
Are you married? (Circle One Response)	YES	NO
If YES, how many years have you been married?		
Do you have any children? (Circle One Response)	YES	NO
If YES, how many children do you have?		
How many people live in your household?		
What is the highest level of school you attended?		
Did you attend public or private school? (Circle One Response)	PUBLIC	PRIVATE
Are you currently employed? (Circle One Response)	YES	NO
If YES, where?		
What is your religion?		

**SECTION TWO**

Have you ever been tested for HIV? (Circle One Response)	YES	NO
If YES, what month and year was your last HIV test?		
If YES, how many times have you been tested for HIV?		

If <b>YES</b> , where did you receive your most recent HIV test (e.g. hospital, dispensary, etc)?		
If <b>YES</b> , did you receive counseling either before or after your last HIV test?		
Do you think you will get tested in the next one year? (Circle One Response)	YES	NO

**SECTION THREE**

<p>From your perspective, what are the top three barriers to getting tested for HIV <u>in your community</u>?</p> <p>Please write down all of the barriers you believe exist. You can use the back of the paper if you need more room.</p>	<p>1.</p> <p>2.</p> <p>3.</p>
<p><b>If you have been tested for HIV</b> in the past, what are the top three reasons for getting tested? Why did you get an HIV test?</p> <p>Please list the top three reasons for getting an HIV test.</p> <p>If you have not been tested for HIV, please skip this question.</p>	<p>1.</p> <p>2.</p> <p>3.</p>

<p><b>If you have NOT been tested for HIV</b> in the past, what are your top three reasons for not getting tested? Why have you not gotten an HIV test?</p> <p>Please list the top three reasons for not getting an HIV test.</p> <p>If you have been tested for HIV, please skip this question.</p>	<p>1.</p> <p>2.</p> <p>3.</p>
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**SECTION FOUR**

<p>In the last 3 months, how many male sexual partners have you had?</p>	<p>Number of male sexual partners: _____</p>
<p>In the last 3 months, how many female sexual partners have you had?</p>	<p>Number of female sexual partners: _____</p>
<p>In the last three months, how often did you use condoms when engaging in sexual intercourse?</p> <p>Always    Very Frequently    Occasionally    Rarely    Very Rarely    Never</p> <p>I've never had sexual intercourse</p>	
<p>How likely is it that you have HIV right now?</p> <p>Not Likely                      Somewhat Likely                      Very Likely</p>	
<p>How likely is it that you will become infected with HIV in the next 3 months?</p> <p>Not Likely                      Somewhat Likely                      Very Likely</p>	

**SECTION FIVE**

<p><b>Please indicate if you think the following statements are true, false, or you don't know.</b></p>			
<p>People are likely to get HIV through deep kissing, or putting their tongue in their partner's mouth, if their partner is HIV positive.</p>	<p>TRUE</p>	<p>FALSE</p>	<p>I DON'T KNOW</p>

There is a cure for AIDS.	TRUE	FALSE	I DON'T KNOW
The virus that causes AIDS can be transmitted from a mother to her baby during breastfeeding.	TRUE	FALSE	I DON'T KNOW
Someone can prevent getting HIV by abstaining from sex.	TRUE	FALSE	I DON'T KNOW
Someone can prevent getting HIV by remaining faithful to a faithful partner.	TRUE	FALSE	I DON'T KNOW
Someone can prevent getting HIV by always using condoms correctly.	TRUE	FALSE	I DON'T KNOW
In a married couple, it is possible for one person to have HIV and the other one not to have HIV.	TRUE	FALSE	I DON'T KNOW
A person can get HIV by giving/ donating blood.	TRUE	FALSE	I DON'T KNOW
It is possible to tell if someone has HIV just by looking at them.	TRUE	FALSE	I DON'T KNOW
<p>Have you ever received an education program about HIV/AIDS?</p> <p>Please Circle One Answer</p>	<p>In primary school/ secondary school/ high school</p> <p>In college or university</p> <p>Training or other program</p> <p>Non-governmental organization (NGO)</p> <p>Church</p> <p>Friends/ family/ the community</p> <p>Other _____</p> <p>I have never received education about HIV/AIDS.</p>		
<p>How well do you believe that your community (friends, family, etc) knows about how HIV is transmitted and prevented?</p> <p>Please circle one response.</p>	<p>My community knows a lot.</p> <p>My community knows some information.</p> <p>My community knows very little/ no information.</p>		

**SECTION SIX**

Do you believe that people who are living with HIV experience stigma or discrimination because of their status?	YES	NO
If yes, who do they experience stigma and discrimination from the most?  Please do not put any names. You can write partner, friend, etc.		
<b>Do you agree or disagree with the following statements (circle one response):</b>		
People with HIV/AIDS should be ashamed of themselves.	AGREE	DISAGREE
I would feel ashamed if I was infected with HIV.	AGREE	DISAGREE
People with HIV/AIDS are dirty.	AGREE	DISAGREE
I would play sports with someone who has AIDS.	AGREE	DISAGREE
HIV is a punishment from God.	AGREE	DISAGREE
I do not want to be friends with someone who has AIDS.	AGREE	DISAGREE
People living with HIV are often excluded from social gatherings.	AGREE	DISAGREE
People living with HIV are often abandoned by their spouse.	AGREE	DISAGREE
Do individuals who are going to get tested experience stigma from healthcare workers/ people who conduct testing?	YES	NO
If you were going to get an HIV test, where would you prefer to go?	The Regional Hospital	

<p>Circle all that apply.</p>	<p>The District Hospital</p> <p>A government health clinic/ dispensary near me (within 5 kms)</p> <p>A government health clinic/ dispensary far from me (more than 20kms)</p> <p>A private clinic or dispensary near me (within 5 kms)</p> <p>A private clinic or dispensary far from me (more than 20kms)</p> <p>A non-governmental organization</p> <p>A testing event in my community (such as a testing program on World AIDS Day)</p> <p>I would prefer to take a home test</p> <p>Other: _____</p>
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**SECTION SEVEN**

<p><b>Please indicate whether you agree or disagree with the following statements.</b></p> <p><small>Adapted from: Boshamer, C. B &amp; Bruce, K. E. (1999).</small></p>		
	AGREE	DISAGREE
HIV test information is kept very confidential by the medical staff who do the testing.	AGREE	DISAGREE
It would be embarrassing to get tested for HIV.	AGREE	DISAGREE
People in my life would leave me if I had HIV.	AGREE	DISAGREE
I am afraid someone would find out I was tested for HIV.	AGREE	DISAGREE
I would rather not know if I have HIV.	AGREE	DISAGREE

Anyone who is tested for HIV is smart.	AGREE	DISAGREE
Getting tested for HIV helps people from getting HIV.	AGREE	DISAGREE

**SECTION EIGHT**

How often do you discuss HIV/AIDS in your home or with your friends in your community?			
Frequently	Occasionally	Rarely	Never
If you do, with whom do you normally discuss HIV/AIDS?  Please do not put any names. You can write partner, friends, best friend, etc.			
How often do you talk about getting tested for HIV with your friends or family?			
Frequently	Occasionally	Rarely	Never
Do you know someone who is living with HIV?	YES	NO	
Do you know someone who has been tested for HIV?	YES	NO	
If you wanted to get tested for HIV, would your family be supportive of that decision?	YES	NO	
If you wanted to get tested for HIV, would your friends be supportive of that decision?	YES	NO	
If you tested positive for HIV, is there someone in your social network that you would tell?	YES	NO	
If <b>YES</b> , who would you tell?  Circle all that apply.	Your husband / wife  Your intimate partner (girlfriend/ boyfriend)  Your best male friend  Your best female friend		

	<p>Another friend/ acquaintance</p> <p>Your Mom</p> <p>Your Dad</p> <p>Your siblings</p> <p>Your teacher</p> <p>Your pastor</p> <p>Your healthcare provider</p> <p>Your peers</p> <p>Your boss/ coworkers</p> <p>A stranger</p> <p>I would not tell anyone</p> <p>Other: _____</p>
<p>In general, how likely is it that someone who is HIV positive is willing to share their status to other people they know in your community?</p> <p>Not likely                  Somewhat likely                  Very likely                  I don't know</p>	
<p>From your perspective, how can we encourage more people to get tested for HIV?</p>	