

MULTIPLE SEXUAL RELATIONSHIPS AND THE STIGMA ASSOCIATED WITH
ANTI-RETROVIRAL THERAPY IN RURAL TANZANIA

Implications for HIV prevention and treatment interventions

THE DEPARTMENT OF PUBLIC HEALTH SCIENCE

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“Education’s purpose is to replace an empty mind with an open one”
Malcolm S. Forbes

ABSTRACT

Background: Risky sexual behavior, HIV-related stigma, and poor access to HIV care and treatment are three interrelated factors in the prevention and treatment of HIV. For every person starting on HIV treatment, there are three who become newly infected, and social stigma hinders enrollment and access to HIV treatment. The scale-up of antiretroviral therapy (ART) in resource-limited settings has been one of the largest public health operations of our time. The current decrease of AIDS funding in Tanzania spawned the investigations in this thesis that simultaneously takes these three interrelated dynamics into account. The primary aim of this thesis is to provide insights that will assist in the development of a nationwide and scientifically sound HIV/AIDS prevention and treatment strategy.

Methods: Qualitative and quantitative research approaches were used to collect and analyze the data. Paper I examines the attitudes, perceptions, and practices among healthcare workers, ART patients, and community members in regards to ART care and the perceived social consequences of the ART rollout. Paper II investigates female-driven multiple sexual partnership systems among both men and women in the community. In Paper III, a population-based survey was conducted as a follow-up to the findings in Paper I. This survey assessed the knowledge and attitudes about ART and ART patients among men and women aged 15 to 49 years old that had heard of ART. In paper IV we estimated the rates of pre-ART care and ART coverage. These values were calculated as the percentage of HIV-positive people receiving care or ART compared to those in need of treatment or care in the Rufiji district ART program from 2005 to 2010.

Results: The primary perception among participants in the studies was that ART was a means to extend life only for a brief period of time. They often employed the expression “marehemu mtarajiwa” or “dead to be” to describe patients on ART. Participants also assumed that ART patients pose a threat to society because they look healthier after starting on ART and intentionally transmit HIV to others (Paper I). Among those who had heard of ART, 24% were poorly informed about ART, 8% were moderately informed, and 68% were highly informed. In regards to ART-related stigma, 28% were the least stigmatizing, 41% were moderately stigmatizing, and 31% were highly stigmatizing toward persons taking ART. Participants who were well informed about ART held less negative beliefs about ART patients (Paper II).

ART coverage increased during each year of the program for women over the age of 25, but decreased for men and those younger than 25 years, the two groups who are not accessing the district ART program (Paper III). Socialization processes undertaken during adolescence have a profound impact on the likelihood of engaging in female-driven multiple sexual partnership systems (Paper IV).

Conclusion: The findings in this thesis capture the variable characteristics of sexual partnerships, ART-related stigma, and access to ART program intervention. They provide the detailed understanding of the sexual behavior, stigma, and ART coverage pattern in Rufiji district that is necessary for the optimal design of both HIV prevention and treatment interventions.

Keywords: ART-related stigma, ART coverage, HIV, Tanzania, stigma, mafiga matatu, initiation rites, risky sexual behavior, multiple sexual partnerships, HIV testing, and counseling.

LIST OF PUBLICATIONS

- I. **Agnarson, AM**, Masanja H, Ekström AM, Eriksen J, Tomson G and Thorson A: *Challenges to ART scale-up in a rural district in Tanzania: Stigma and distrust among Tanzanian health care workers, people living with HIV and community members*. Trop Med Int Health. 2010 Sep; 15 (9): 1000-7.
- II. **Agnarson, AM**, Levira F, Masanja H, Ekström AM and Thorson A: *Antiretroviral treatment knowledge and stigma – implications for programs and HIV treatment interventions in rural Tanzanian populations*. PlosOne. 2013 Jan; 8 (1): e53993.
- III. Levira F, **Agnarson, AM**, Masanja H, Basia Z, Ekström AM and Thorson A: *Antiretroviral treatment coverage in a rural district in Tanzania– a modeling study using empirical data*, (Manuscript).
- IV. **Agnarson, AM**, Strömdahl S, Levira F, Masanja H and Thorson A: *Female-driven multiple sexual partnership systems in rural part of Tanzanian province*, (Manuscript).

The publications and manuscripts are referred to in the thesis by their Roman numerals (I-IV)

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BACKGROUND

UNIVERSAL ACCESS TO ANTIRETROVIRAL THERAPY

About 30 million people have died from Acquired Immune Deficiency Syndrome (AIDS) since the first reported cases in 1981, and an estimated 34 million people are living with human immunodeficiency virus (HIV) in low- and middle-income countries (Anonymous 1981, UNAIDS 2011).

Currently, about 54% of HIV-positive people that need antiretroviral therapy (ART) in Sub-Saharan Africa (SSA) have access to ART (WHO/UNAIDS/UNICEF 2011). In 1996, the introduction of a new class of antiretroviral drugs (ARVs), protease inhibitors, and combination therapies with at least three different ARVs radically changed the prognosis for HIV-positive individuals (Egger et al. 2002, Mocroft et al. 1998). Additionally, ART has effectively reduced the vertical transmission of HIV from pregnant women to their infants (Volmink et al. 2007).

In 2003, only 1% of the individuals in need of ART worldwide had access to it through private, for-profit, or pilot projects (Charles and Boyle 2002, McConnell 2002). This low coverage was the impetus for the '3 by 5 Initiative' of the World Health Organization (WHO) that sought to scale-up the provision of ART to reach 3 million HIV-positive people in need of ART by 2005 (Traynor 2004). This initiative, despite not reaching its target goal, ensured that 1.3 million people had access to ART in 2005 (WHO-UNAIDS 2006). In 2006, a new target aiming for universal access to HIV treatment, prevention, and care was set in 2010 by the international community (WHO-UNAIDS 2006).

The goal of universal access is a part of Millennium Development Goal (MDG) 6 that includes the objective of reversing the spread of HIV/AIDS by 2015 (UNAIDS 2011). Various studies have demonstrated that providing ART is cost-effective by improving quality of life, encouraging employment, and increasing economic revenues (Granich et al. 2012, Marseille et al. 2012). At same time, the scale-up of ART involves significant challenges including the need for a general understanding of the value of sexual partner reduction, HIV testing and succeeding in ART treatment, guaranteed access to ARVs, assistance for patients in adhering to treatment, and sufficient health infrastructure and healthcare personnel.



Health system and policies

Figure 1: Major dependent health system building blocks. Reproduced from de Savigny and Adam (2009).

Healthcare is at the core of all health systems and accounts for one of the largest areas of spending by both governments and individuals. The components of a health system are its people, institutions, and resources (WHO 2000), and the primary objective

of a health system is to ensure the quality of care and safety of the people it serves (WHO 2009). The 2007 report “Everybody’s Business: Strengthening Health Systems to Improve Health Outcomes” deconstructs health systems into six operational building blocks: service delivery, human resources, health information systems, access to essential medicines, financing, and leadership/governance (Mikkelsen-Lopez et al. 2011, WHO 2007) (Figure 1). Service delivery is a direct output of the inputs into the health system, such as the healthcare workforce, the procurement and supply of essential medicines, and financing. Leadership/governance and health information systems form the basis for healthcare policy and regulate all of the other health system blocks (WHO 2009).

Health policies in HIV care and treatment

The success of ART scale-up largely relies on assumed health policies taken by governments or donors to reform other interconnected policies. Health policies are the decisions, plans, or actions that seek to attain specific healthcare objectives within a society. The WHO states that health policy should define a vision for the future, outline priorities and the expected roles of various groups, and build on a consensus that informs people as to the responsibilities and benefits associated with the policies (WHO 2007).

The implementation of an HIV care and treatment policy depends on the government’s health expenditure capacity. A strong and receptive health system is able to efficiently incorporate any policy that will lead to improved health for individuals communities (Walt and Gilson 1994). Investments of time and effort in disease control, quality of healthcare delivery, health promotion, or policy-making will fail if the health system itself is inattentive or weak (Reich et al. 2008). For example, the demand and burden that HIV care and treatment sets on the health system often surpasses the capacity of the system making HIV care and treatment a matter for civil society, private organizations, and donors (Windisch et al. 2011).

Countries often report challenges in monitoring the adherence of patients to ART regimens due to a lack of coordination between multiple, parallel ART programs (Obua et al. 2011), and donor nations often use their own government health policies to formulate health policy for recipient nations (Balabanova et al. 2010). An example of this is the new set of standards promoted in 2010 by the WHO and its partners that call for ART initiation when CD4 cell counts fall to or below 350 cells/ μ L (WHO 2010). Most SSA countries have had difficulties in implementing this policy because they lack the financial capacity to do so (Braitstein et al. 2006, Klein et al. 2003).

ART eligibility and monitoring

The assessment of ART eligibility includes both medical eligibility (clinical staging and CD4 count) and social eligibility (the patient's willingness, readiness, and ability to receive ART) (WHO 2010). Before commencing therapy, the patients must have accepted their HIV-positive status and be clear as to the consequences of HIV infection and sexual behavior change, the role of ART to the persons’ health, and the need to strictly adhere to the treatment plan.

Measurements of CD4 cells are essential for grading the severity of the disease, monitoring the health of HIV-positive individuals and determining their eligibility for ART (O'Brien et al. 1997). The CD4 count is expressed as the absolute number of CD4 cells per microliter of blood. A low CD4 cell count is associated with increased mortality, and a CD4 count of 200 or lower indicates that a person may be vulnerable to opportunistic infections (Lundgren et al. 2008). In SSA countries, the yearly cost of quarterly CD4 cell counts and viral load measurements extends beyond the cost of first-line ART regimen (Walensky et al. 2009). Consequently, the CD4 count service is only offered once every 6 or 12 months, and the WHO clinical staging standard is used as the routine diagnostic tool (Keiser et al. 2008).

Different HIV disease stages correspond to the WHO clinical stages. A transient flu-like syndrome associated with sero-conversion corresponds to WHO clinical stage 1, a symptomless period corresponding to a CD4 cell count above 350 cells/ μ L corresponds to WHO clinical stage 2, and a symptomatic period involving opportunistic infections of varying severity, weight loss, and a CD4 cell count below 200 cells/ μ L corresponds to WHO clinical stages 3 and 4.

HIV-related stigma

The stigma associated with HIV is dynamic and changes with the phases of the epidemic in a given community (Herek 1998, Nyblade 2006a). It also varies with physical manifestations of the disease; a person in the asymptomatic stage is less vulnerable to stigmatization compared to a person suffering from wasting syndrome (Herek et al. 1999, Parker and Aggleton 2003). Parker and Aggleton suggest that stigmatization and discrimination is a communal and cultural fact that is ingrained in wider social processes of power and domination, inequality, and poverty (Parker and Aggleton 2003). Stigma and discrimination manifest themselves within families, communities, schools, employment, travel/migration opportunities, and health care settings (Baltazary et al. 2011, Kingori et al. 2012, Muhamadi et al. 2010, Van Tam et al. 2011). There are numerous types of stigma, including anticipated stigma, experienced stigma, secondary stigma, internalized stigma, compound/layered stigma, and observed stigma. HIV-related stigma is a negative association with people's incorrect beliefs about HIV/AIDS and HIV-positive people (Nyblade 2006b), and discrimination describes the actual acts that are carried out to disadvantage HIV-positive individuals (Parker and Aggleton 2003).

Gender and sexuality

An individual's sex is the phenotype expressed by their genome, but gender describes what it means for them to be male or female in a certain society. Gender roles are absorbed through socialization (Logan et al. 2002), and age, social class, race, ethnicity, and religion, along with geographic, economic, and political environments, influence gender roles (2000, Turmen 2003). Gender norms often hinder efforts to reduce the HIV epidemic, and Dunkle states that "the global HIV pandemic cannot be effectively arrested without fundamental transformation of gender norms (Dunkle and Jewkes 2007)."

An example of socialization process is initiation rites that are conducted in a number of communities in SSA (Arnfred and Nordiska 2005, Holm 1986, Richards 1982). Initiation rituals facilitate the process of conveying community-held attitudes, beliefs, and practices to young people (Swantz 1969). Tamale describes the sexual education within the initiation rites as being based upon an ancient matricentric foundation. Through female and male instructors, the apprentice is integrated into the community, and this ensures interpersonal transfer of sexual and cultural knowledge from one generation to the next (Tamale 2011).

Multiple concurrent sexual partnership

Having multiple sexual partners increases the risk of acquiring HIV infection. A meta-analysis of 68 epidemiological studies from 1986 to 2006 on HIV infection rates found that women who reported three or more sex partners had three times the likelihood of acquiring HIV compared to women with up to two partners (Chen et al. 2007).

The concept of multiple concurrent sexual partnerships (MCP) is defined as “overlapping sexual partnerships in which sexual intercourse with one partner occurs between two acts of intercourse with another partner” and has dominated discussions of multiple partnerships (Halperin and Epstein 2004, Halperin et al. 2004). Multiple partnerships are serial relations with intercourse not occurring at same time (Powers et al. 2011). Tanser suggests that an increase in the number of lifetime partners for men (multiple partnering) raises the individual risk of sero-conversion (Tanser et al. 2011). MCP reduction remains a strategic target for HIV prevention programs because long-term concurrent partnerships are usually an indication of large networks of sexual partners and risky behavior in such large networks may result in higher HIV transmission rates (Morris and Kretzschmar 1995).

TANZANIA

Tanzania is a country located on the East African coast bordering Kenya and Uganda to the north; Rwanda, Burundi, and the Democratic Republic of the Congo to the west; and Zambia, Malawi, and Mozambique to the south. Mainland Tanzania is divided into 21 regions and 125 districts. The population is about 43.7 million people, 75% of which live in rural areas. The annual population growth rate was 2.7% in 2009 (UNDP 2010), and in the same year the average life expectancy at birth was 56 years (UNDP 2010). In 2010 the per capita income was US\$ 509 and the total per capita expenditure on health was US\$ 31 (WDI 2012).



Figure 2: Map of Tanzania & region HIV prevalence

The first cases of AIDS were initially observed in the Kagera region at the end of 1983 (Mhalu et al. 1987). The HIV epidemic is not spread evenly throughout the country (Figure 2) and consists of significant regional differences. For example, Iringa has the highest HIV prevalence of 15.7%, and Manyara has the lowest HIV infection rate of only 1.5% (The National Bureau of Statistics Tanzania and Macro 2008). The average national HIV prevalence rate is 5.7% with women being infected more than men (6.8% versus 4.7%). HIV prevalence in young women between 15 and 24 years of age is 3.9%, which is more than twice the prevalence of 1.7% seen in men of the same age. The HIV prevalence among women rises sharply with age from 1% among women aged 15 to 19 years to a peak of 10% among women aged 30 to 34 years and then falls to a rate of 7% among those aged 45 to 49 years. Among men aged 15 to 49 years, the HIV rate rises more gradually with age to a peak rate of 10% among those aged 35 to 39 years and declines to 6% among men aged 45 to 49 years.

According to population-based estimates, HIV rates in urban areas are almost twice those of rural areas. HIV prevalence is lowest among those never married followed by those who are married, cohabiting, or divorced. HIV prevalence is highest among widowed women and reaches rates as high as 25.1% in this group (TACAIDS 2012).

Tanzania health care system and policies

After the Arusha Declaration of 1967, the government of Tanzania placed an emphasis on self-reliance and declared free access to healthcare for all citizens. Health service delivery was under control of the central government and was free of charge at all levels. The government introduced a number of health sector reforms, including decentralization of healthcare administration, shifting resources from curative to preventive care, and creating insurance schemes for employees to address capacity and performance problems (Garbus 2004, URT 2009).

The health care system in Tanzania can be divided into three levels. The primary level consists of dispensaries, health centers, and district hospitals. The secondary level comprises regional hospitals that provide both basic and specialized services. The tertiary level consists of six hospitals that are primarily responsible for specialized health services (Garbus 2004). In 1995, the government introduced a cost-sharing policy for health services (Garbus 2004), but antenatal care (ANC), family planning, and tuberculosis and HIV care are exempted from user fees. For the poorest quintile, the ability to pay for health care depends a great deal on contributions from their social network (Mtei et al. 2012, Muela et al. 2000).

In addition, the healthcare system is currently operating with a 40% shortage of the required skilled workforce (Manzi et al. 2012, Munga and Maestad 2009).

HIV care and treatment response in Tanzania

The Tanzania Commission for AIDS (TACAIDS) coordinates the nation's response to the HIV and AIDS epidemic. In 2004 the government began providing free ART to patients with

CD4 counts less than 200 cells/ μ L or who were WHO stage 3 or 4. Since that time there has been an increase in the number of care and treatment clinics (CTCs) and the number of people on ART (TACAIDS 2012, The National Bureau of Statistics Tanzania and Macro 2008).

In 2010, about 825 CTCs provided HIV care and treatment services in the country, and the national adult ART coverage was at 42% (WHO/UNAIDS/UNICEF 2011). Overall, twice as many women in Tanzania were on ART compared to men, and the majority of patients (71.6%) were in the 25 to 49-year-old age group. The lowest rate of participation in ART (4.4%) was seen in the 15 to 24-year-old age group.

Preventing mother to child transmission (PMTCT) services are integrated into routine reproductive and child health services, and the percentage of pregnant women who tested positive for HIV and who received ARVs increased from 55% in 2008 to 70% in 2010. Despite this progress, however, PMTCT is not a priority in district health plans. Consequently, local governments do not allocate resources to support PMTCT activities in the districts and this results in difficulty in implementing these services (NACP 2011).

Governance and financing of HIV care and treatment response in Tanzania

Tanzanian HIV prevention strategies are formed in a highly heterogeneous policy setting and are heavily dependent on international funding. This results in donor- and politics-driven HIV prevention policies (Hunsmann 2012). About 97% of HIV-related expenditures are donor-financed (TACAIDS 2010) and external aid for HIV control accounts for more than 10% of the total public expenditure. In addition, 85% of donor spending directed for HIV/AIDS is off budget and thus not subjected to oversight control by government systems. This impacts adversely on the government's HIV prevention and treatment plans. For instance, the National Multi-sectoral Strategic Framework (NMSF) 2008–2012 prioritizes prevention (URT 2009), but fulfillment of this initiative has not been achieved because the government lacks the mandate to oversee the funding, planning, and management of NMSF implementation (TACAIDS July 2012).

The majority of current HIV/AIDS spending in Tanzania (59%) goes towards care, treatment, and support, 23% goes towards prevention interventions, 9% is budgeted for program management, and the remaining 9% covers the costs of impact mitigation (TACAIDS 2010).

Continued subsidization of the national HIV/AIDS control response strategies is uncertain at present due to issues concerning the two major donors. Major donors have not shown any interest in future subsidies, and the Global Fund has announced that it will not solicit additional HIV and AIDS proposals until 2014 (Bilimoria 2012, Moszynski 2011). Furthermore, a number of the development partners have reduced their support for the years beyond 2012. The Tanzania AIDS Control Trust Fund (TACTF) is currently being formed as a way to solicit funds to make up for the upcoming deficit in financial support (TACAIDS 2010).

AIMS AND OBJECTIVES

OVERALL AIM

To analyze the challenges to the continuation of ART programs, to explore social structures related to sexuality and concurrent multiple sexual partnerships, and to contribute to improved HIV care and interventions for the reduction of risky sexual behavior.

OBJECTIVES

- To explore the attitudes and perceptions towards the scale-up of ART among healthcare workers, ART patients, and community members in rural Tanzania (Paper I).
- To assess the magnitude and level of ART knowledge and ART-related stigma among men and women in rural Tanzania (Paper II).
- To estimate ART coverage, i.e. the percentage of HIV-positive people receiving ART among those in need of treatment in the Rufiji district ART program in rural Tanzania (Paper III).
- To explore the connection between initiation rites and *mafiga matatu*, and to explore gender-specific strategies to cope with and manage the socio-economic transactions within the *mafiga matatu* sexual partner system in a society that traces descent on the maternal line in Tanzania (Paper IV).

METHODS

RUFII DEMOGRAPHIC SURVEILLANCE SYSTEM

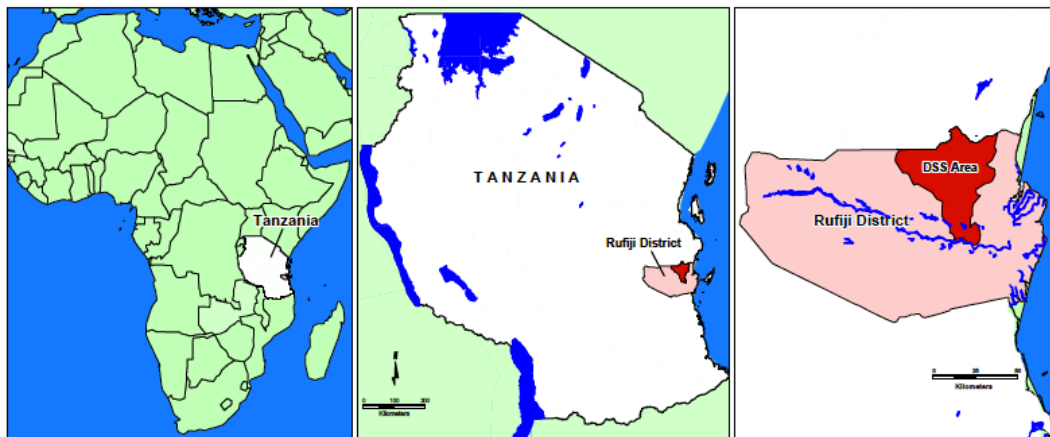


Figure 1: Rufiji district in Tanzania and the Rufiji demographic surveillance site (DSS) (Njau et al. 2009).

This study was conducted in collaboration with the Ifakara Health Institute (IHI) in Tanzania. The IHI is an autonomous, non-profit, district-based health research and resource institute that runs the DSS in the Bagamoyo, Rufiji, Mtwara, and Kigoma districts. The Rufiji Demographic Surveillance site (RDSS) commenced field operations in November 1998 as one of the four major components of the Tanzania Essential Health Interventions Project (TEHIP).

The RDSS employs the Household Registration System (HRS), which involves collecting and documenting data on pregnancies and births, deaths, causes of death, immigration and emigration, and demographic information on age, sex, education, occupation, marital status, and household socioeconomic data. Routine data is collected on household members. Each survey period takes four months to complete and households are visited in sequence. Each registered household and members of the household are assigned a unique identification number that serves to permanently identify individuals and households. During these rounds, ad hoc research projects are included. The site covers the total population in the six contiguous wards of Bungu, Kibiti, Ikwiriri, Mchukwi, Mgomba and Umwe and also extends to the district quarters in Utete in regards to specific health issues.

The demographic characteristics of the RDSS

The RDSS monitors a total population of 93,000 people in 18,000 households in 32 villages in a rural coastal area situated around a river delta in the Pwani region south of Dar es Salaam in Tanzania. The economy is based predominantly on subsistence farming and fishing. The Ndengereko are the district's largest ethnic group, followed by the Matumbi, Ngindo, and Zaramo. Swahili is the lingua franca and the population of Rufiji is 90% Muslim followed by

Christians and other religions (EDI 2007). The area is a transitional matrilineal descent society with patriarchal power relations (Beidelman 1967, Hamdani 2001, Wembah-Rashid 1975). This means that the line of descent is traced through the female line and the society is separated into clans that acknowledge common descent. The majority of the population practices a patrilocal residential pattern, which is where a couple settles to live close to the husband's father after their marriage. In this setting, paying a bride price is customary. In some residences the patterns are duo-local, with the mother and children staying at her maternal house and the husband staying at his.

HIV care and treatment infrastructure within Rufiji district

There are 55 health facilities in the district, including 2 hospitals (1 government and 1 mission), 5 government health centers, 44 government dispensaries, and 4 non-government dispensaries (de Savigny et al. 2004). There are nine centers in Rufiji District where blood screening and counseling services are provided. The national ART program is integrated into the existing healthcare system, and both private and private for-profit agencies exist within the same system. In 2010, the Pwani region had 28 CTC units with 23,212 patients enrolled in pre-ART care and 9,985 patients commencing with ART (TACAIDS 2012). In 2005, an ART scale-up pilot program at the district level was started at Mchukwi Mission Hospital. By 2010 the ART program had extended to Utete District Hospital (2006), Nyaminywili Health Centre (2009), Nyamisati Dispensary (2009), Ikwiriri Health Centre (2010) and Kibiti Health Centre (2010).

The rationale for basing the thesis in the RDSS

The lack of population-based data in many low-income countries hinders the development of effective health programs. The DSS provides vital information that enables health planners to determine the overall effectiveness of the health system and to monitor the health status of the local population. These systems have become a tool for generating evidence for action on a broad spectrum of public policies. According to the ARVMAC project plans and agreements with the local government, the vital information from this thesis is being sent to the District Medical Officer and the Regional Health Commissioner for them to use in their strategic plans for HIV care, treatment, and prevention interventions in the district.

ARVMAC PROJECT

This thesis is part of the Effects of Antiretrovirals for HIV on African Health Systems, Maternal and Child Health (ARVMAC), an FP6 INCO-DEV European Commission-funded project that aimed to assess the health system consequences of the rapid scale-up of HIV treatment programs. The project operated between 2006 and 2010 in three SSA Health and Demographic Surveillance Sites (HDSS): The Iganga-Mayuge DSS in Uganda, the Nouna DSS in Burkina Faso, and the Rufiji DSS in Tanzania.

Seven project partners were active in the project including the Karolinska Institutet (Sweden, coordinator), the Makerere University School of Public Health (Uganda), the Swiss Tropical and Public Health Institute (Switzerland), the Ifakara Health Institute (Tanzania), the Institute of Tropical Medicine, (Belgium), the University of Heidelberg (Germany), and the Nouna Health Research Centre (CRSN) (Burkina Faso) (www.arvmac.eu).

STUDY PARTICIPANTS, RECRUITMENT, AND DATA COLLECTION

Table 1: Summary of study design, methods, and participants for Papers I–IV

Paper	I	IV	II	III
Study setting	Rufiji demographic surveillance site, Tanzania			
Study design	Qualitative		Quantitative	
Data collection	Focus group discussions (FDGs), In-depth interviews (IDIs), ethnographic participant observations		Population-based cross-sectional survey	Analysis/modeling of data from routine CTC data
Instrument	Thematic interview guide		Questionnaire	Health facility record review
Data collection & Study participants	FDGs = 26 healthcare workers and men and women from the community IDIs = 44 healthcare workers, key community participants, ART patients, and men and women from the community		Men and women aged 15–49 years. (n = 694)	Men and women enrolled in Pre-ART care and started on ART between 2005 and 2010. (n = 4300) Secondary data from the RDSS
Analysis	Latent content analysis		Latent class analysis Multivariate analysis	ALPHA age-specific mortality modeling

The specific objectives for each study, literature reviews, and fieldwork experience guided the qualitative and quantitative research approaches of this thesis. Table 1 summarizes the overall study methods, data collection strategies, and data analysis methods.

In Paper I, we explored the attitudes, perceptions, and practices among healthcare workers, patients, and community members in relation to the ART scale-up. The findings from Paper I guided the structure and content of Paper II in which we examined ART-specific knowledge, beliefs, and attitudes as well the level of stigma among adults in a population-based, cross-sectional survey.

In paper III, longitudinal data including 4300 patients aged 15–49 years from six CTCs in the Rufiji district were analyzed to examine age-specific ART care and ART coverage from 2005 to 2010.

For paper IV, we explored the mechanisms, processes, strategies, and relationship dynamics of female-driven MCP.

Latent content analysis was used for qualitative data analysis (Papers I and IV). Latent class analysis (LCA), bivariate and multivariate analyses (Paper II), and mathematical modeling (Paper III) were applied to the quantitative data.

Papers I and IV

Field work training

We conducted the interviews and ethnographic participant observations over a period of 16 months. Two female social scientist undergraduates were recruited from the University of Dar es Salaam, and one female and one male were recruited from the RDSS. The team spent two full weeks of training in qualitative research methodology, including familiarization with the project and its goals as well on ethics and confidentiality.

Interview guides

A thematic interview guide (Dahlgren et al. 2004, Patton 2002) was developed from literature reviews and formative fieldwork and was used to conduct focus group discussions and in-depth interviews. The guide was initially designed with basic themes and was gradually modified as the fieldwork expanded and new themes emerged from interviews. Kvale argues that this form of interviewing is less intrusive to those being interviewed, and introduces the possibility of probing for further details (Kvale and Brinkmann 2009). For the interview session, one research assistant and I would moderate the interview while at least one other assistant was taking notes and observing. The interview started with general conversation before taking on specific questions.

Recruitment

RDSS staff placed in different locations in the villages assisted with recruiting participants in 2007. As I got to know the environment, I started to recruit participants through village leaders and, subsequently, through my fieldwork team members. The District Medical Officer assisted in recruiting for healthcare worker interviews. He initially informed concerned staff about our presence, and he also organized the interviews with the district AIDS coordinator and the district spokesman for HIV-positive individuals.

In-depth interviews (IDIs) with traditional healers and *kungwe* were organized by first attending their sessions, after which the request for an interview was expressed. These interviews sometimes took a day to carry out because often both the healer and *kungwe* invited us to spend the day or night before we were given an interview.

Focus group discussion

Focus groups are “collective conversations” (Liamputtong and Ezzy 1999), that provide the “means to set up a negotiation of meanings through intra- and inter-personal debates” (Hennink 2007). The hallmark of focus groups is the explicit use of the group interaction to generate data and insights that would be unlikely to emerge without the interaction found in the group (Dahlgren et al. 2004, Kitzinger 1994).

We employed focus group discussions (FGDs) prior to the IDIs to explore the diverse individual perspectives and attitudes on how sexuality, stigma, and HIV are articulated, censured, and opposed as well as how the different terms are related to societal norms. Participants were purposely recruited based on age (the participants were divided into age groups of 15–24, 25–35 or 35–45 years) and gender (women and men were interviewed separately, except for three mixed-group FGDs among healthcare workers in Paper I in which the sampling was based on occupation rank) and an emphasis was placed on having the largest possible variety of occupations represented (Patton 2002). Each session consisted of 6–10 participants and lasted for about 90 minutes.

In-depth interviews

In-depth interviewing is a type of interview that researchers use to elicit information to achieve a holistic understanding of the interviewee’s point of view or situation (Patton 2002). The key informant interviews aimed to investigate attitudes and perceptions on ART among community members, healthcare workers, and ART patients (Paper I). Secondly, the methodology was used to elicit concepts, values, and meanings related to men’s influences on multiple sexual partner systems and transactional sex (Paper II).

Ethnographic participant observations

The unstructured interview technique was developed in the disciplines of anthropology and sociology as a method to elicit people’s social realities (Agar 1996, Kvale and Brinkmann 2009). Gall (Gall et al. 2007) maintains that the unstructured interviewing technique relies entirely on the spontaneous generation of questions in the natural flow of an interaction and thus captures the true nature of an event or subject. I used ethnographic participant observations to gain an understanding of the social processes in which the objectives of our study play out. I tried to summarize the notes according to the questions ‘who?’, ‘what?’, ‘when?’, ‘why?’, and ‘how?’ that are often used in the field of journalism (Stovall 2005).

Paper II

Structured interviews

In a structured interview approach, each interview uses the exact same questions in the same order, and this guarantees that answers are collected consistently and that comparisons can be made with some degree of certainty between sample subgroups (Oppenheim 2004). The items used in the questionnaire in Paper II were designed based on the findings from Paper I as well as validated items from studies conducted in other SSA countries (Agnarson et al. 2010). We used a cross-sectional study approach that facilitated comparisons of men and women of different age groups and socio-economic backgrounds in terms of their perceptions, attitudes, and knowledge. Potential bias was limited by dividing the entire target population into different subgroups and then randomly selecting the final subjects proportionally from the different strata (Robson 2011). The questionnaire covered four themes: HIV care and treatment awareness, ART knowledge, ART-related stigma, and HIV-related stigma. The questionnaire was translated into Kiswahili and piloted by an RDSS interviewer whose suggestions on changes were incorporated into the final questionnaire.

Sampling

A stratified sample was drawn from the RDSS adult population aged 15–49 years that is distributed over 32 villages. The population was divided into three age groups (15–24, 25–34, and 35–49 years) and according to gender. The three age and two gender groups were multiplied by the number of villages to get 192 strata. The probability of selection of from each sampling strata was proportional to the estimated sample size, and 4 or 5 individuals were drawn from each strata.

Paper III

In paper III we sought to analyze the annual progress of the ART scale-up in the district from 2006 to 2010. The district follows the national ART program that entails different recording and reporting tools (Somi et al. 2012c). The district medical officer assisted in data collection by informing the relevant health facilities about our visits. A spreadsheet matching the CTC forms was created prior to data collection and the information was transferred into the spreadsheet according to the CTC forms. Patient data were retrieved from pre-ART and ART registries and cross-sectional and cohort analysis reports.

Three patient reporting and recording systems were used in the district, including monthly reports summarizing the number of people who had ever been enrolled in pre-ART care or in ART, quarterly reports summarizing the number currently in pre-ART care and in ART, and quarterly cohort reports summarizing the status of people enrolled in pre-ART care and in ART (NACP 2009). The patient data was obtained from Pre-ART and ART patient registers, monthly and cross-sectional reporting tools, and cohort report monitoring tools. The data were collected across the registries by using the 7-digit HIV patient national identifier. The data

collection process was begun in September of 2009 and completed in January of 2011.

District estimates for the total population were obtained from updating the 2002 national census (Macro 2002, UNDP 2010), the age and sex-specific HIV prevalence was taken from the national HIV survey, and the Weibull representation on HIV specific mortality was obtained from the Kisesa cohort (ALPHA network).

ANALYSIS OF DATA

Papers I and IV

Latent content analysis

Qualitative analysis is an “iterative spiral process” that starts with learning the data, moves on to describing, classifying, and connecting the data, and ends with accounting for the data (Dey 1993). Content analysis examines what the words or concepts used by participants mean. There are two approaches in content analysis, manifest and latent. According to Patton, the latent approach conveys what the participants actually mean rather than what is being said (Patton 2002). The latent content analysis procedure was applied to Papers I and IV.

The analysis process began while still doing fieldwork and the analysis guided the themes that were included in ongoing interviews. The first step in the process was to transcribe and translate the interviews verbatim from Kiswahili to English by a research assistant and myself. Because of the large amount of material, two other translators continued with the process.

The transcripts were read repeatedly followed by inductive content analysis through an open coding process (Mustone 2007). The purpose for using an inductive approach was to condense the data into a brief summary format as well as to establish clear links between the research objectives and the findings derived from the raw data. As opposed to a priori codes that are developed before examining the data, inductive (emerging) codes are developed by the researcher while examining the data (Kvale and Brinkmann 2009). During open coding, the data were broken down into discrete parts (Graneheim and Lundman 2004), and the text segments that contained meaning units were labeled and categorized. Additional coding was done and new categories emerged. This was followed by sequentially combining the categories into focused categories from which the final themes emerged (Graneheim and Lundman 2004).

The initial coding was carried out independently and then together with the research team, and coding discrepancies were resolved via consensus between the authors and de-briefing from research peers conducting similar research. Discussions with staff members from the RDSS and with research assistants that were involved in data collection were carried out iteratively to contextualize the findings.

Ethnographic participant observations

The ethnographic participant observation material consisted of fieldwork journals, notes, jottings, pictures, digital recorded diaries and drawings that were read and indexed through mind mapping in the FreeMind version 05 software package. The analysis process involved reflecting on words, notable sentences, phrases and expressions, and descriptions of contexts and events. Ultimately, the coded field notes were reviewed and fitted to the concepts suggested by the interview data.

Paper II

Descriptive analysis

The data was organized and linked to the household registration database to match with the individuals' characteristics such as education, marital status, and employment status. A descriptive analysis was generated for these socio-demographic variables for individuals that had heard of ART and those who had not.

Latent class analysis

Latent class analysis (LCA) is best described as an “improved” cluster analysis that uses statistical (rather than mathematical) methodologies to construct the results into categorical output. In its basic form, LCA is a statistical method to identify subgroups that have related values in a set of observed indicator variables (Lanza et al. 2007). It can be used in any situation where the presence of clusters of persons, organizations, or other units is assumed. Apart from the variables used to identify the latent classes, external variables can be included in the model as covariates affecting the class membership. A class is characterized by a pattern of conditional probabilities that indicate the chance that variables will take on certain values (Nylund et al. 2007).

Three-step latent class analysis

Three-step latent class analysis was applied in Paper II. We established the basic latent class model for ART knowledge, ART-related stigma, and HIV-related stigma. We then adjusted for education, gender, occupation, and marital status as predictors for class membership. Finally, we used a latent class multinomial logistic regression model to investigate the relationship between levels of ART knowledge, ART-related stigma, and HIV-related stigma as outcome variables and the covariates of education history, occupation, gender, and marital status as the explanatory variables. We also assessed the associations between the outcome variables. The regression model was selected based on minimum Chi-square goodness of fit criteria. The created models treated missing data as missing at random, meaning that all available data were used to estimate the model by using full information maximum likelihood (Lanza et al. 2007).

Paper III

The ALPHA model

The Analyzing Longitudinal Population-based HIV/AIDS data in Africa (ALPHA) network was established in 2005. The ALPHA network comprises ten community-based HIV serological surveillance sites that collaborate in demographic and epidemiological analyses of their data (LSHTM 2012). The model estimates the maximum need for ART by those who are HIV-positive by calculating the proportion of people who would be expected to die within a fixed interval of time in the absence of treatment. The estimates are disaggregated according to the sex and age characteristics of the HIV-positive population and take into account the effects of treatment programs on life expectancy for infected individuals (Case 2010, Zaba et al. 2008).

Assumptions

There are two assumptions included in the model:

- (i) The 3-year survival time from eligibility to death in the absence of ART is equivalent to the eligibility criterion of having a CD4 count of 200 cells/ μ L.
- (ii) The age-specific HIV mortality pattern prior the introduction of ART is same for women and men and this applies to all treatment-naïve HIV-infected populations in East Africa (Collaborative 2008). In addition, we have assumed that HIV prevalence patterns observed in the Pwani region can be applied across all the districts in the region.

Estimating the proportion of HIV-positive in need of ART

Fitting a Weibull model to the observed and pooled mortality data from the ALPHA cohort sites before the availability of ART at each site (Crampin et al. 2012) generated two parameter estimates, the overall mortality level (λ) and the rate that mortality increases with age (ϕ). Weibull parameters of $\lambda = 0.0094$ and $\phi = 1.59$ were determined from the Kisesa cohort (one of the ALPHA network member sites located in northwest Tanzania) prior to the ART era and were applied to the Rufiji district estimates (LSHTM 2012, Zaba 2012).

In the first year of implementation of the ART program, the proportion of individuals in need of treatment among HIV-positive persons was estimated from the proportion of those expected to die in the next three years in the absence of treatment (Zaba et al. 2007). In the subsequent years of the program, the ALPHA estimation model adjusted the treatment need while accounting for improved survival due to the availability of treatment by estimating the proportion of newly eligible patients by sex and age based on the same pre-treatment mortality pattern. The number of people who need pre-ART care is the difference between the estimated number eligible for ART treatment and the entire HIV-positive population.

Estimating pre-ART care and ART coverage

The number of HIV-positive individuals in the district was obtained by multiplying the district population by the regional HIV prevalence as determined from the household-based 2007/8 Demographic and Health Survey (DHS) (The National Bureau of Statistics Tanzania and Macro 2008). The number of people receiving treatment is an estimate of patients that had visited the ART clinic at least once during the last quarter of the year (NACP 2009). The estimation is derived using three main inputs:

- A. The number of all patients who visited the ART clinic for treatment in the last quarter of each year.
- B. The cumulative number of patients from the start of the program to a specific year (excluding A).
- C. The ratio of A to B in each year (Mahy et al. 2010, Zaba et al. 2007).

Age-specific pre-ART care and ART coverage estimations were calculated by adding A to the product of B and C.

ETHICAL CONSIDERATIONS AND RESEARCH PERMISSIONS

Formal permission was sought from the District Medical Officer prior to performing fieldwork in healthcare facilities. Detailed written and oral information and the opportunity to discuss the project with the research team were provided in connection to the FGDs and IDIs. Even though some of our participants were willing to be identified by their real names, for the sake of both privacy and uniformity no names have been used. Instead, only broad descriptions have been provided that lack specific details.

During the formative fieldwork process in the healthcare facilities, healthcare staff sometimes pointed out people or provided names of their clients during informal conversations. Cautions were taken on multiple levels. First, fieldworker assistants signed confidentiality agreements to not discuss or share such information in any form with anyone other than the research team. Second, because the names of some of the people we worked with and the names of community members were found in the databases, only the principal investigators (myself and a Tanzanian colleague) collected the CTC data, and identifiers by name were not recorded. The information and data sets acquired in this work were used only for the intended purposes of this research and were not shared with any other party not involved in the research.

Dealing with dilemma in participant observation

Ethnographic participant observation is an iterative process that tacit the development to understand meanings, events and context. Participant observational research also deals with

the question of how much personal information a researcher should disclose (O'Byrne 2012). Conducting research on secretive and sensitive issues surrounding sexual behavior and HIV in particular social settings and among transient and local participants led to the conclusion that it was best to keep one's objective hidden as protection for the participants. In other situations, for example when participating in group activities such as *Unyago* and *Rusha roho* parties, I explicitly informed the host about my position as a researcher on HIV without going in-depth into the exact study area (Paper IV).

I used the knowledge and experience from observations to negotiate my position in the setting, to design the guidelines for interviews, and helped to recognize nuances within participants responses (Maunsbach and Dehlholm-Lambertsen 1997). I observed how people interacted, conducted discussions, and subsequently applied similar cultural cues during the interview. My observations and inquiries also placed me in a vulnerable situation and sometimes in ethical dilemmas. For example, during late night activity field observations I had to guard my own and the female research assistant's well-being and safety. I often pretended to have a drink or blamed my sensitive stomach for not having drinks. Because of the nature of the context during the late night activities (darkness), I observed unpleasant and unethical events, sometimes by people familiar to me. I felt the obligation to intervene, which I sometimes also did.

In addition to that, I constantly worried over exploiting my research participants, as well as breaching the confidentiality. I was conducting the research together with other researchers, a set up that required me to share information on what was going on in the study. I found myself struggling with not breaching the confidentiality and keeping my professionalism and obligation to my colleagues. The difficulty in information sharing became obvious when I revisited the field in 2009, together with my Swedish female colleague. In particular it was difficult to not disclose previous informal interviews with my regular participants without breaking the code of confidentiality during joint fieldwork. Therefore, I decided to not disclose and share authentic field notes with my colleagues. During the joint analysis process I had changed the names and places where certain events took place before sharing the data, to ensure confidentiality.

RESULTS

This chapter summarizes the results of Papers I–IV. I have also included additional data that was not included in those articles to further underscore the objectives of this thesis. In qualitative findings, in some quotations, the Swahili terms are kept to retain the participant's voice and to contextualize the findings, especially where a precise translation has been difficult. Specific details such as names, ages, and places have been modified to protect the confidentiality of the research participants. Where lines have been omitted this is indicated by spaced dots.

Participants in the study often understood ART to be a means to extend life only for a brief period of time and employed the expression “*dead to be*” [marehemu mtarajiwa] to describe patients on ART. Participants also assumed that ART patients pose a threat to society because they look healthier after starting on ART and will intentionally transmit HIV to others (Paper I). Among those who had heard of ART, 24% were the least informed about ART, 8% were moderately informed, and 68% were highly informed. In regards to ART-related stigma, 28% were the least stigmatizing, 41% were moderately stigmatizing, and 31% were highly stigmatizing towards persons taking ART. Participants who were highly informed about ART held less negative beliefs about ART patients (Paper II).

ART coverage increased during each year of the programme except for men and youths below 25 years of age who were not accessing the district ART programmes (Paper III).

Socialization processes undertaken during adolescence form the basis for the collective motivations for engaging in multiple sexual partnerships. Older women are the ones who are upholding and supporting the female-driven multiple sexual partnership systems (Paper IV).

PAPERS I & II

The main objective of Paper I was to investigate the attitudes and perceptions towards ART scale-up among healthcare workers, ART patients, and community members. To follow up on the findings from Paper I, the extent of ART knowledge and ART-related stigma among men and women that had heard of ART was determined among 455 survey respondents who had heard of ART (Part II).

Community experience and perceptions of HIV testing (Paper I)

When discussing HIV care with community participants, the majority pointed out the inadequate training of the healthcare staff at the facilities providing HIV care. Community members experienced communication barriers in their interactions with healthcare professionals. The participants also said that the lack of comprehensive knowledge about HIV and preventive measures among healthcare workers, in addition to the fear of stigma from the community, was a significant discouragement to many from seeking HIV care and treatment services. This is illustrated by the following quote from an HIV-positive male informant

from an IDI:

My wife was pregnant and she went to the clinic, (...) they told her to bring me there. I went there and did the check-up; they told me I was HIV positive and my wife needed to use the ARVs to protect my child from HIV. I got confused and told them that our blood made that child. How can this medicine protect the baby from the disease? That doctor shook his head and said, "I cannot know about that, they told me to advise you to use the medicine. I just give you the advice to use the medicine." The doctors and nurses, they don't care about us, they don't know anything.

Participants further said that they experienced pressure from healthcare workers to be tested for HIV when they had sought care for other reasons. Other participants described the HIV testing and counselling process as unnecessary, and that it often caused fear among those seeking help. They also held the belief that there is no cure for HIV so all of the talk from the healthcare workers was, in a way, pointless. The quote below is from a woman participating in an FGD and illustrates how the counselling procedure introduced fear and worries rather than being supportive:

When a person comes for testing, that person is questioned. Whenever you are questioned a great deal about something that you already made a decision on, the person questioning you is creating a fearful feeling in you. There is no need to question a person much in this [HIV testing], because this is a disease that already lacks a cure.

Community perceptions and knowledge on ART (Papers I and II)

Community participants said that ART had an "expiry date" and that starting ART treatment was perceived as nothing more than giving the HIV-positive person enough time to design his or her coffin. This distrust about the longevity of ART seemed to be founded in the notion that people who started on ART did not live long on ART.

ARVs are there to prolong life, but people do not live longer after eating such medicines. It doesn't take even two, three or four months before one dies.

This perception was articulated in many informal conversations with community participants. Disparaging idioms such as "*the dead to be*" [Marehemu mtarajiwa] or "*the inadequate*" [si riziki] were used in the discussions about people on ART.

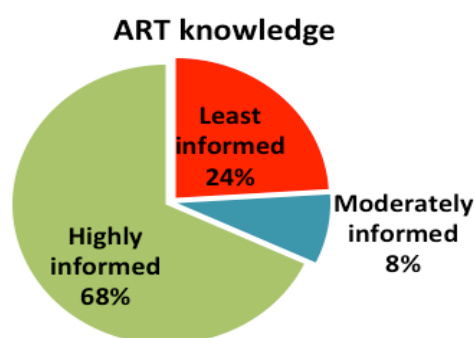
At the same time there were participants who believed that the use of ARVs could help and that it was possible to change the community perception towards ARVs. The same participants emphasized that the community needed to see and know people who are receiving ART before they could fully embrace the benefit of ART. A male participant in an FGD explained this as follows:

You know this dose [ARVs] when we look at it carefully they are very helpful. I have seen a person who tested positive for HIV since 1980 and she is in good health today. Still it depends

on people's environment, how they live, and their beliefs. Some things you can't believe until you see.

Level of ART knowledge among men and women

From the follow-up study (Paper II), about one third of the 455 respondents who had heard about ART knew that an HIV-positive pregnant woman could be on ART, and around 70% were aware that ART was provided free of charge from hospitals (Table 2). About 21% stated that ART prolongs life, and 34% believed that ART improves health. Forty-seven per cent were aware that ART is a life-long treatment. Few respondents (8%) thought that ARVs should be used only when HIV-positive individuals are very ill.



Based on the participants' response pattern to ART knowledge items, three latent classes of ART knowledge level were constructed; 24% of respondents were *least informed*, 8% were *moderately informed*, and 68% were *highly informed* about ART (Figure 6). Participants who had at least a primary education level were more knowledgeable about ART compared to participants with no formal education (Odds ratio (OR) 3.09, 95% confidence interval (95% CI) 1.61-5.94).

Figure 3: Three latent class models of ART knowledge; least, moderately, and highly informed about ART.

Community perceptions and beliefs about people on ART (Papers I and II)

Male and female participants stated that before the introduction of ART they avoided HIV exposure by looking for signs of body wasting in a person. Participants were now worried that such signs could no longer be used as a result of ART, and this seemed to produce fear among the participants. Furthermore, the participants also placed the responsibility for this on the government for reinforcing this situation by providing the ART treatment to HIV-positive people. A male participant along with the other FGD participants lamented on the issue:

Having that disease of AIDS, AIDS means it is a person who is like a dying tree. Okay [the group agree], then at the same time the Government is providing medicines to make that tree to become healthy.

Participants also insisted that their perceptions towards people on ART were grounded in what was being said by those who were using the medications. The following quote from a male

participant in an FGD exemplifies how community members reasoned about how they believe people on ART are intentionally transmitting HIV to others:

Yes, it is like that, for example when you have given me the medication [ARVs] and I will become fat, I will regain my normal health. Then themselves they tell you, now they have their saying, “I can’t go alone, we die together.”

The level of stigmatizing attitudes towards people on ART (Paper II)

The LCA produced three ART-related stigma classes; 28% of the respondents belonged to the *least stigmatizing* class, 41% were *moderately stigmatizing*, and 31% were *highly stigmatizing* towards persons taking ART (Table 3). A notable result from the latent class model was that 94% of the individuals in the *highly stigmatizing* group were more likely to describe ART patients as “*dead to be*”, and that they would “*die soon*” (99%). These latent class outcomes illustrate that the community universally uses the discouraging term “*dead to be*” against a person on ART. The multinomial logistic model showed that participants with *high HIV-related stigma* were likely to hold *highly stigmatizing* (OR 61.57, 95% CI 55.40–72.50) perceptions about people on ART. Further, participants who were *highly informed* on ART tended to express less stigmatizing attitudes towards people on ART (OR 0.26, 95% CI 0.09–0.74).

Table 2: The latent class units for ART-related stigma

Three latent class model on stigmatizing attitudes towards ART patients (n=455)			
	Least stigmatizing	Moderately stigmatizing	Highly stigmatizing
Proportions	0.28	0.41	0.31
	<i>Conditional probability of stigmatizing response*</i>		
ART patients are a threat to society	0.19	0.76	0.81
ART patients are intentionally transmitting HIV	0.07	0.49	0.89
ART patients look healthy after taking ARVs and transmit HIV to others	0.10	0.44	0.99
ARVs increase sexual drive for ART patients	0.07	0.43	0.78
ART patients are “ <i>Dead to be</i> ”	0.76	0.99	0.94
ART will die soon	0.30	0.59	0.99

*Estimated conditional probabilities and for each latent class based on “Yes” responses to the items.

Bold numbers denote the most recurrent answer within the class for each statement.

PAPER III

Longitudinal data including 4300 patients aged 15–49 years from six CTCs and population-based data were used in a mathematical model to project district-wide age-specific pre-ART care and ART coverage between 2005 and 2010.

Proportion of HIV-positive individuals in need of ART

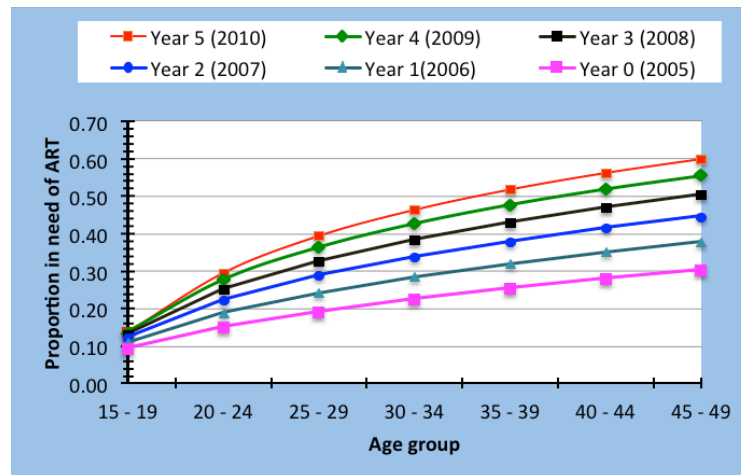


Figure 4: Proportion of HIV-positive adults that need to start on ART by age and programme year. This data was generated from the ALPHA age-specific mortality model.

Due to the cumulative effect of increased survival and age among HIV-positive people on ART, the number of people that need ART has increased gradually by year and age (Figure 4). The first ART treatment programme was piloted in the district in the end of 2005. Thus the year 2005 was defined as year one and 2010 marked the fifth year of the ART programme in the district. The proportion of HIV-positive people in need of ART increased each of these years in each age group, and the number of people in need of ART doubled after five years of the ART programme. Comparing the age-specific and total numbers across all years combined, more women than men needed treatment because there was higher number of HIV-positive women than men.

Pre-ART care coverage

A total of 1771 women and 721 men had been enrolled in pre-ART care over the study period. Forty-seven (1.8%) deaths were reported among the women and 27 (1.1%) deaths were reported among the men. More than twice as many females as males were enrolled.

The majority of patients were enrolled in pre-ART care while in WHO clinical stage 2 (35%) or 3 (39%) between 2005 and 2010. Only 7.3% had been enrolled while in WHO clinical stage 4. A total of 23% of the patients were lost to follow-up, and 1.4% of the women and 0.5% of the men were transferred to clinics outside the district.

About 4%, 8%, 14%, 22%, and 30% of the total estimated HIV-positive population in the district were enrolled in pre-ART care in 2006, 2007, 2008, 2009, and 2010 respectively (Figure 5). The enrolment into Pre-ART care increased exponential over the five years period.

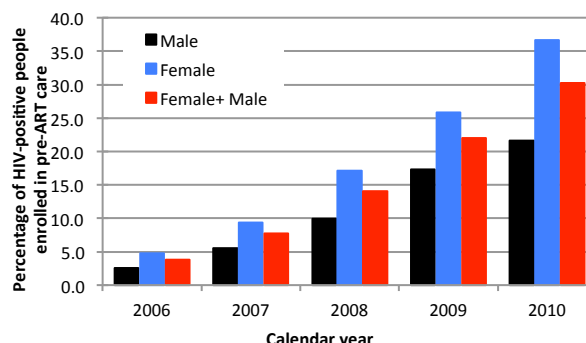


Figure 5: Estimated pre-ART care coverage from 2006 through 2010

Characteristics of all patients ever initiated on ART

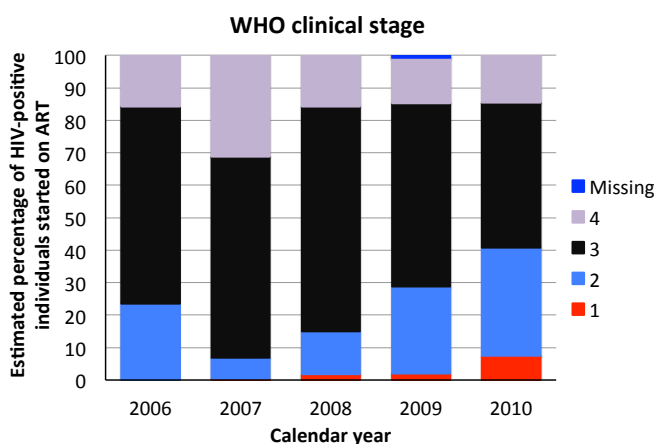


Figure 6: WHO clinical stage at the start of ART

One thousand four hundred two HIV-positive adults (70% women) in the district started on ART between 2005 and 2010. The majority of those who started on ART were in WHO clinical stage 3 (58.3%) followed by stage 2 (21%), stage 4 (18%), and stage 1 (3%). From 2008 onward, more individuals began to start on ART in WHO clinical stage 2 and 1, compared to the two previous years (Figure 6).

CD4 cell counts showed that 321 (23%) of the patients had less than 100 CD4 cells/ μ L, 392 (28%) had between 100 and 250 CD4 cells/ μ L, and 348 (25%) had 250 or more CD4 cells/ μ L. No CD4 counts were available for 340 (24%) of the patients registered in ART treatment.

ART coverage

The overall district ART coverage improved each year during the five years of the study. The estimated percentage of HIV-positive individuals on ART was 10%, 23%, 31%, 37%, and 43% in 2006, 2007, 2008, 2009, and 2010, respectively (Figure 7).

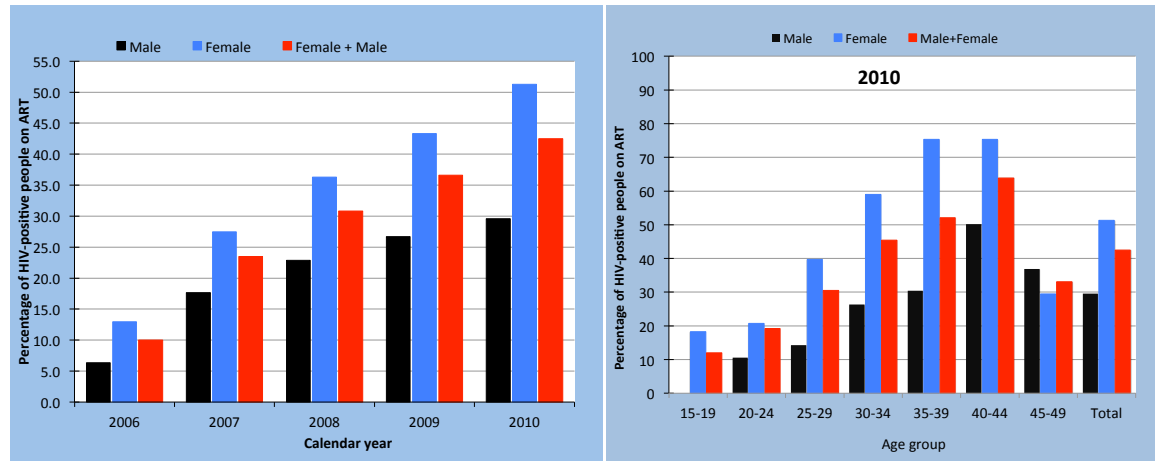


Figure 7: Estimated ART coverage from 2006 through 2010, and age-specific ART coverage in 2010

Age-specific ART coverage

The ART coverage, defined as the percentage of HIV-positive people on ART, varied widely among different age groups in both sexes with women having higher coverage (estimated at 18% to 75%) than men (estimated at 0% to 50%). The age groups of 15–24 years and 20–24 years had the lowest coverage of 12.0% and 19.2%, respectively, compared to the overall average coverage of 43% for all age groups in 2010. ART coverage for men aged 15–19 years was less than 1% compared to 18% for women in the same age group in 2010. There is a clear peak age for ART coverage between the ages of 34 and 49 years, and coverage falls off for those aged 45–49 years (Figure 5).

PAPER IV

The findings from this paper are presented as the themes and categories that emerged from the data analysis. Initial coding produced meaning units and selective codes. Further examination of the patterns and relationships between these codes led to the development of one main theme and its sub-themes. The first sub-theme; *practicing and denouncing*, was that both men and women either engaged or did not engage in extramarital activity, but still denounced the practice. The second sub-theme; *communicating and strategizing* (Allen et al. 2007) highlighted how the female driven multiple sexual partnership system was negotiated, justified, communicated and internalized within the society.

A social insurance system based on sexual relations

Women's extramarital relationships were described according to the structure of *mafiga matatu*. In this system, the woman is the cooking pot balancing on the three stones of her husband/steady partner and two lovers. Figure 5 illustrates the relationships of a woman from 29 to 32 years of age who is married a farmer. This woman had employment with a monthly salary of around 50,000 sh/TZ (equivalent to around 31 \$US). She commenced the relationship with her current husband (her 1st stone) and then with her 2nd stone, whom she referred to as *Mvumba* (fish smell), a local term for money. *Mvumba* feeds her with money, goods, and sexual pleasure.

He brings me big fish [money], maintenance, other times he will help my children. When I have nowhere to find help or support. He smells fish [money], (...) he knows how to take care of my middle path-my vagina [njia yangu ya katikati].

She started her relationship with her 3rd stone, whom she referred to as *Kabwela* (single man) after her marriage to her current husband.

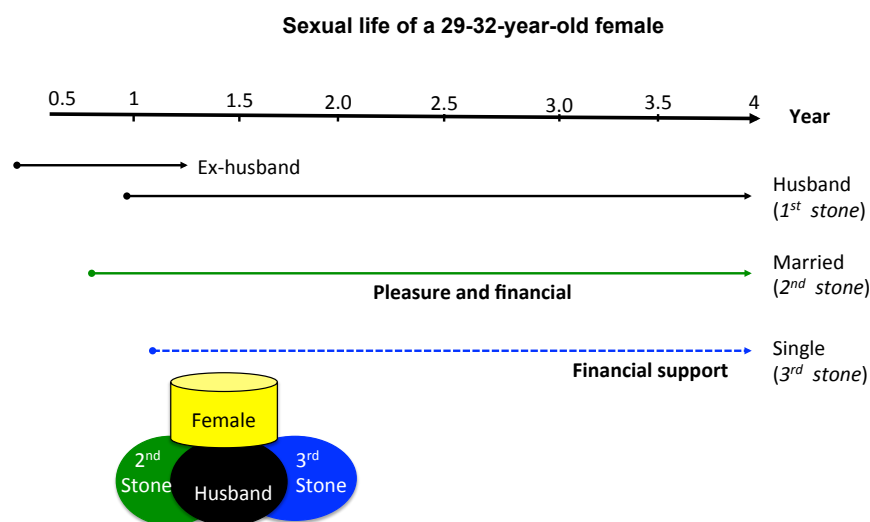


Figure 7: Description of the *mafiga matatu* system of a married woman from 29 to 32 years of age. She has two sexual relationships outside her marriage. The figure also illustrates the structure of *mafiga matatu*, a wife balancing on top of the husband or steady partner and two lovers.

Men also conducted extramarital activities similar to women. Men described their mistresses as *thermometers*, a metaphor for a woman who will keep the man warm (Figure 10).

My true partner, she cares for my children and me. The first thermometer [vipima joto-mistress], I don't enjoy having sex with her because she is lazy in bed, I only enjoy the conversations I have with her. The second woman works hard in bed to please me, but she is not a good discussant. I keep up with her because she works hard.

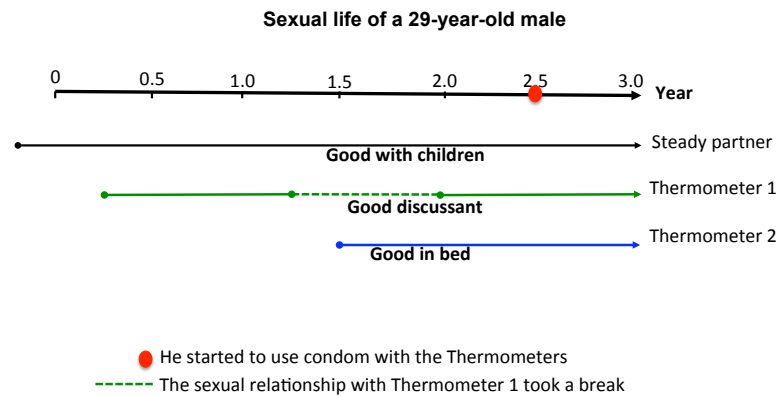


Figure 8: Sexual life of a 29-year-old male who is keeping three separate sexual relationships that include steady partner for three years (black), a second partner who he has been with on and off during the last three years (green), and third partner (blue).

Practicing and denouncing

Women seeking sexual pleasure and financial support

Female participants said that not engaging in *mafiga matatu* means that one is prone to suffer from hunger and emotional starvation. Among those women who sought sexual pleasure and were not interested in attaining financial support from their lovers, the explicit justification for their activities was that such activities were supported by predominating cultural attitudes. A 23-year-old woman, in conformity with other women during an FGD, expressed the following reasoning:

In Christianity, it is not acceptable to have other men once the person is married. When a person decides not to take on another man, that person has to understand that by not having another man, they will starve physically and emotionally [wao watakufa njaa ya kimwili na kihisia].

Men dealing with and preventing extramarital activity

The norm observed and quoted among our interviewees was that men are the absolute head of the household. However, male participants often held the perception that their spouse attains

financial stability through the practice of *mafiga matatu*. The mutual understand between the women and their husbands on the practice holds as long as the female is discrete about her activities. A 41-year-old male participant, who was at the time of the interview involved in two other relationships outside his marriage, explained the importance of *mafiga matatu*:

The man has the authority; a wife is placed in terms of mafiga matatu. If I only place her on me she might not be stable, it is not possible for the woman to stay in that relationship. There will be times I will be out in the farm, (...) preparing charcoal or sick. She will not have any help if she is not engaged in mafiga matatu.

At the same time, there were male participants that were against the idea of their wives having another man. These men did not trust their spouses, and several reported threatening and assaulting their spouses as a way to discourage them from taking on lovers.

Other men described joint responsibilities or making sure that the wife has the necessary financial needs before leaving the house. Many men, especially those that had relationships outside their marriages, emphasized keeping the wife at home with money, as lamented by a 37-year-old male participant in an FGD:

I have a Kisado [small house], to the wife at home I leave her some money so as she doesn't go and sleep with someone else. The aim is to make sure she has money so that she doesn't develop that desire to get the money from someone else. I give twenty per cent to the woma outside [the mistress] and fifty per cent to my wife at home because she is the mother of my children.

Communicating and strategizing

Female schemes to nourish and maintain the support from lovers

The woman was obliged to plan her extramarital activities in a way that will generate good and sustainable support. The participating women described the system as similar a system of family planning, referring to the Green Star family planning programme intervention. This strategy involved the woman switching between the two lovers to gain the most from each of them. A female participant described this in an informal interview:

A skilled farmer does not cultivate the same crop on the same land each season [Mkulima mwenye ujuzi, hakulima mazao juu ya ardhi moja kwa kila msimu] (...) it does not give a good harvest because that soil lacks nutrients for a good harvest, (...) during one season I cultivate peas (...) then the next season we allow the soil to regenerate, (...) as we relocate the crop to a different area (...) it is the same thing with establishing assistance from lovers.

Women further described that extramarital relationships required a lot of effort and skill from the woman. Female participants also explained that the system of having two lovers did not always work in practice. The quote below is from a woman in an FGD that suggests that

women ask for support simultaneously from their lovers in the hope that one of them will be accommodating to her request:

It is an individual choice to have two other men. It is not that if my man today is unable to give me money for food, then if I go to the next one he will give me money. That is what we as women think first. It requires hard work to get money from a man.

Participants described a woman that frequently took on new lovers as promiscuous and not managing her financial assets well. They thought she was “*transporting one trip gravel and sand in the next trip*”-meaning she is not choosing her men according to rules that would give her the best financial support. At same time, participants also maintained that if the lover runs out of the means to support the woman, the woman should temporarily replace him.

Grandmothers teaching and maintaining the *mafiga matatu*

For the majority of participants, *Unyago* (initiation rites), which include the teaching of *mafiga matatu*, institute social order and equip women with necessary life skills. From participant observations, we were able to observe that phrases used by both men and women indicated that the motivation to engage in *mafiga matatu*-based sexual relationships had its source in the initiation teachings. The following description is reproduced from a song drawn from a teaching session in one of the *Unyago* ceremonies that we attended:

Keep the balance in your house child, don't starve [usikufe na njaa]. Keep one foot in the house and one foot outside [mguu mmoja mbirini, na mguu mmoja nje].

The woman should avoid any emotional bond to the lover as this creates the risk for indiscretion, and she could lose the support of both lovers as well as the husband. The quote below is from a *kungwe* in an IDI that suggests that women not to get too much involved in the lover.

If you are engaged too much with him [the lover], the fish [money/income] you have will be ruined. The second lover will avoid you, to avoid problems.

Participants expressed that although religious leaders denounce the practices of *mafiga matatu*, they had difficulties in enforcing any changes on the practice of *mafiga matatu* in the community. Men and women stated that going against these grandmothers in the community was seen as an act of disrespect.

DISCUSSION

In this thesis, I found a lack of trust among the community in the sustainability of ART care, a lack of community trust in the care itself, and a lack of trust in the healthcare provider's skills. Community participants described that HIV-positive people often engage in risky sexual behavior after starting on ART (Paper I). This mistrust was more prevalent among respondents with lower education levels and less knowledge about ART (Paper II). Furthermore, women in partnerships were establishing extramarital relationships based on the teachings during initiation rites ceremonies to attain substantial financial, physical, and emotional support from their lovers. Men expressed support for the wife having sexual partners outside the marriage (Paper IV).

Community experience and perceptions on HIV testing (Paper I)

For treatment programs to be sustainable, a reduction in HIV incidence is a must. New infections can be prevented through high-quality HIV testing and counseling (HTC) (Wolfe et al. 2008, Wringe 2008), and receiving HTC through extensively trained counselors has been found to have an impact on patients' risky sexual behaviors (Cremin et al. 2010).

Participant considered HIV counseling to be "pointless interrogation." This is a point that the global community needs to consider. A study conducted with people that had taken an HIV test or were about to take the test found that people preferred to take an HIV test promptly without accompanied counseling (Joseph et al. 2011). The fear introduced before the person has taken the test might also lead to people failing to receive the results of the test or not paying attention to the advice offered to them.

HIV testing services are the first line in HIV care and treatment, and for measures to have an impact on a person's sexual behavior they should start here. However, the preventive opportunities are often missed because the people responsible for this task lack the necessary training and resources. Participants described how they experienced HIV testing to be mandatory and felt unable to decline a test. At the same time, the healthcare workers acknowledged the need for adequate training. This finding should be considered in light of PITC scale-up (Fonner et al. 2012, TACAIDS 2012) where few resources are being allocated for proper and sustainable training for healthcare workers. Taking measures to train healthcare workers has the potential to improve ethical conduct and their understanding of counseling (Moszynski 2008).

Proper counseling by a knowledgeable healthcare worker may reduce risky sexual behaviors and improve community attitudes towards ART and people on ART. In Tanzania, among those that take an HIV test only 17% that test HIV-negative and 25% that test HIV-positive receive their results (Isingo et al. 2012). Trust in health services and professionals providing the services have been presented to be an important constituent of individual and community acceptance of health services (Gilson et al. 2005).

Lack of schooling, ART knowledge, and ART-related stigma (Paper I-IV)

In Paper I, we identified that participants assumed that people on ART were intentionally transmitting HIV to others once they had started on ART. Other studies in Tanzania have found similar findings (Roura et al. 2009). In Paper III, more than one third of men and women in the study reported that they had never heard of ART, and among the participants that had heard of ART it was maintained that ART users were a threat to society because they intentionally transmit HIV to others. They believed that this was due to the fact that ART patients look healthy after taking ARVs and transmit HIV to others. Maughan-Brown argues that despite the provision of HIV prevention messages along with ART scale-up, stigma is still on the rise (Maughan-Brown 2010).

Stigma affects access to and use of HIV treatment to such a degree that people often travel long distances to access ART in other communities or simply default from the treatment to avoid being stigmatized (Gilbert and Walker 2010). Zou found that individuals who lacked schooling and lacked ART knowledge were less willing to start on ART (Wringe et al. 2012). Taking medications is seen as an indication of an increase in risky sexual behavior rather than as a possibility for people to change their risky behavior (Paper IV).

A study in Uganda found that people on ART experienced high levels of stigma (Nattabi et al. 2011). Another study conducted among people on ART in Mozambique found no change in the level of stigma still experienced one year after starting on ART (Pearson et al. 2009). Insufficient ART coverage in this fairly high HIV prevalence setting (Paper III) might as well contribute to discrimination towards HIV-positive people. The fact that it was widely believed that people on ART intentionally transmit HIV to other probably had a profound impact on the multiple sexual partnership systems found in the same setting (Paper IV).

After adjustment for ART knowledge and HIV-related stigma, there was no association between ART-related stigma and the level of schooling, although participants that lacked formal schooling (about 30% of participants that had heard of ART) also had the least knowledge of ART. The participants that were least informed about ART also held more stigmatizing beliefs about people on ART. These findings underscore that stigma is challenging to forecast but important to monitor, and the crucial need for the introduction of mechanisms to reduce stigma. In agreement with current findings, Genberg established that negative attitudes towards HIV-positive people were correlated to a lack of knowledge on ART (Genberg et al. 2009), and Wringe found a significant association between a lack of education and low access to ART (Wringe et al. 2012). It means that this group that stigmatize the most (II), probably have least access to treatment.

Inequity in HIV care and treatment utilization (Paper III)

The proportions of those enrolled in pre-ART care and who started on ART varied by age, with those in the older age groups being most likely to have initiated ART. The findings show that individuals below 25 years had disproportionately low access to pre-ART care and ART care. Importantly, the results showed that overall ART coverage was 18% and 21%

among 15–19 year olds and 20–24 year olds, respectively, in 2010. HIV care and treatment coverage for men aged 15–24 years was consistently below 10% over the years (Paper III). This low figure among this age group is distressing bearing in mind that men and women aged 15–24 years account for 40% of all new HIV infections in 2012 (Jewkes et al. 2010, Peltzer et al. 2009), and also live longer in ignorance of their positive HIV status and thus can infect others. The latest data show that 42% this young group reported having more than one sexual partner in the previous 12 months, and 30% of those reporting multiple partners did not use condoms during their last sexual encounter (Exavery et al. 2011). HIV prevention, care, and treatment schemes are, essentially, not reaching this group.

Inequity in access to HIV care and treatment among young people has been shown before in Tanzania (Wringe et al. 2012), but the longitudinal nature of our study makes our findings different. Factors influencing access to HIV services have not fully been addressed in this group. The data from SSA show that only 15% of young women aged 15–24 years and 10% of young men the same age had ever been tested for HIV to confirm their HIV status (UNICEF 2011). In addition, comprehensive knowledge of HIV transmission and prevention is lower among the age group of 15–24 years in Tanzania (The National Bureau of Statistics Tanzania and Macro 2008). Young people may also lack the social and economic power to control the impact of the epidemic in their lives, including personal income to pay for transport to healthcare services or access to healthcare information (UNAIDS 2012b). The profound ART-related stigma (Papers I & II) and mistrust in healthcare workers (Paper I) most likely contribute to preventing young patients from utilizing HIV care and treatment services.

The results of this study show that the majority of people that have access to care and treatment are men and women aged 30–44 years (Paper III). This is encouraging because this age group represents a significant portion of the workforce in Tanzania, which has been severely affected by the HIV epidemic (Pennap 2011). High access to HIV care and treatment services among this group has the potential to avert the dire consequences of the epidemic on productivity and health expenditures.

The disadvantages of being a man in HIV care and treatment

The proportion of HIV-positive people in need of ART increased each year and doubled after five years of the ART program. However, only an estimated 30% of men in need of ART in the district were on treatment in 2010. By comparison, 52% of women eligible for ART were on ART by 2010. The male to female ratio has consistently been higher for women compared to men over the years (Paper III). The findings are consistent with the higher HIV prevalence among women compared to men, with 30% more women testing HIV-positive than men (The National Bureau of Statistics Tanzania and Macro 2008). In SSA, women constitute about 60% of people living with HIV and have an average of about a 60% increased risk of infection compared to their male counterparts (Magadi 2011). In addition, women have additional entry points into HIV care, for example through ANC and PMTCT that secure access for women (Le Coeur et al. 2009).

The finding that fewer men have access to or are accessing HIV care and treatment is in accordance with other studies in Tanzania (Wringe et al. 2012). This reflects the fact that most men had received information on ART from TV/radio in comparison to women (Paper II). There has been an increase in the number of HTC sites and Provider initiated testing and counseling (PITC) sites in Tanzania, but the above result suggests that HIV testing scale-up strategies are not enough to increase the proportion of males enrolled in pre-ART care and starting on ART. However, the proportion of men who are aware of their HIV status has increased by 50% during the last few years in Tanzania (TACAIDS 2012).

Men are disadvantaged in access to HIV care and treatment, and once they receive care they are often lost during treatment, either through loss of follow-up or death (Somi et al. 2012a). Men had higher mortality and attrition rates compared to women and this might partly be explained by men's lower baseline CD4 counts (Somi et al. 2012b).

Treatment as prevention strategies that seek to provide ART to everyone at the time of diagnosis are being formulated to increase participation and utilization of HIV care and treatment (Cohen et al. 2012, UNAIDS 2012a). This approach provides measures beyond safe sex and abstinence (Paper IV) that have been only marginally effective in reducing new infection rates and such new measures might maximize the use of ART among men. At the same time, higher community HIV testing rates in Tanzania do not relate with higher uptake of ART or equitable HIV care and treatment coverage among those eligible for it (Wringe et al. 2012). However, the combination of scaling up voluntary medical male circumcision (MMC) and ART has been shown to be more cost-effective in terms of high ART coverage and reduced mortality among men (Barnighausen et al. 2012).

A social insurance system based on sexual relations (Paper IV)

The findings from Paper IV have generated insights into the social norms that circumvent the context of HIV prevention, care, and treatment in rural settings in Tanzania. It has also provided a deeper understanding on metaphors used to describe extramarital sex in Tanzania. The term "*Thermometers*" seemed to relate more to male indulgence, while the *mafiga matatu* system indicated more focused on striving for household financial security.

The participants and the ethnographic participant observations revealed a system that is managed and monitored by authoritative elderly women and that has its origin in initiation rites. In Tanzania, the practice of *Unyago* initiation rites (excluding female genital mutilation) have been described among the matrilineal descent groups of the Zaramo, Ndengereko, Makonde, Hehe, Luguru, Kaguru, and Matumbi tribes (Beidelman 1967, Caplan 1976, Mamuya 1972, Wembah-Rashid 1975). Swartz and Van de Walle underscore that initiation rites are important in the process of socializing the child into specific social gender roles, and thus hold the key to a proper and expected social life (Swantz 1969, Van de Walle et al. 1995). Because of the sexual content in the teaching, several scholars are speaking out against the practice as a way of preventing sexual risk taking among adolescents (Malisha et al. 2008, Philemon 2007).

Various participants in the study explicitly disapproved of the practice but covertly either engaged in the practice or supported the practice. Women and men both viewed sexual pleasure as a legitimate reason to seek extramarital relations, exposing that it is not only the economic setting that drives the extramarital activities but the lack of sexual pleasure in their spouses or primary relationships that is a major contributor to the practice. Helle-Valle discusses extramarital relationships in Botswana termed *Bobotele* that belonged to a distinct context (sex for pleasure) that was different from marital settings (sex for procreation) (Helle-Valle 2005). Similar to the aforementioned findings, the multiple sexual partnership system is deeply integrated in the society and exists as a separate system from sex for procreation.

The complexities underlying the practice of *mafiga matatu*. Men and women described the practice of a woman having several male sexual partners as a way to introduce stability and avert hunger and starvation. In matrilineal descent groups, a woman and her maternal clan still hold the greatest responsibility for her offspring (Schneider and Gough 1961). A woman's ability and skills in providing sexual satisfaction might be a promising way to attract resources and economic support and maintain stability in the clan. Yet, during the data collection, even men and women that were not native to the study setting idealized the practice.

Sexual empowerment of women through education and economic empowerment that increase women's social capital reduces HIV risk (Greig and Koopman 2003, Nyanzi et al. 2005). Mahmud and Holvoet argue that economic interventions such as micro-credit programs work to promote women's household bargaining power (Holvoet 2004, Mahmud 2003). Women from the poorest households are more likely to engage in multiple concurrent partnerships compared to women from the richest household according to previous studies (Mah and Halperin 2010). The findings in Paper IV underscore that the transactions within a relationship extended beyond economic gains as they also revolved around ensuring that they have exclusive privileges over the female partner. Male participants described how they rationed their financial resources around the partners outside the marriage and the primary partner. The transactional component between conjugal couples was described as a necessity to keep other men out and to ensure fidelity from the female partner. Mistrust between spouses has been reported to expedite extramarital activity (Gipson et al. 2010).

Stoebenau concludes in a multi-country SSA study that the constituent transactions within multiple sexual partnerships are connected to the processes of consumerism (Stoebenau et al. 2011). It is important to emphasize that many participants described the focus of *mafiga matatu* system as insurance for possible future economic disasters rather than securing funds for daily consumption. These transactional relationships are nourished more through cultural expectations that are reinforced by elder women in the community than immediate needs. Elder women cultivate and nourish this doctrine in young women at an early stage of life. This, in addition, constructs a forced acceptance among men as well as cultural acceptance for them to engage in sexual risk behavior.

In addition, many men and women discussed joint family responsibilities as a way to avert engaging in the multiple partnership system in marriage, which signify that not all men and

women are accept and embrace the system that is to provide themselves with multiple partners.

METHODOLOGICAL CONSIDERATIONS

Qualitative approach (Papers I&IV)

Sandra Harding concedes that social research is a socially embedded activity that is inevitably tied to one's cultural biases, influences, and prejudices (Harding 1991). The process of analysing qualitative research involves continuous reflexivity and excruciating scrutiny.

Reflexivity

I'm a Tanzanian/Swedish female that was born during the early 1980s in Karagwe, in north-western Tanzania. Shortly after my tenth birthday, I left Tanzania and moved to Sweden. I did not return to Tanzania until the early 2000s. In Sweden I grew up living with my aunt and her family in a relative pure Swedish community. During this time I retained kin-based social networks in Tanzania, which was particularly important to keep Kiswahili and Kinyambo (my mother tongue) as lingua franca. Prior to embarking on this research project, I had pursued a Master of Science degree in Molecular biology, and I had been working as laboratory assistant at the Swedish Institute for Communicable Disease Control, Smittskydds Institutet (SMI). To pursue research in Tanzania also became a way to get in contact with my roots again and to understand my wounds from my childhood experiences related to HIV.

However, direct at my arrival, in particular during the first meetings with community members, my colleagues from the RDSS introduced me to the community as an HIV researcher as well as *"our sister who has been away from home for a long time, and she is completely novice to our culture"*. In addition to that, I was married and had a child with a Swedish white man. Suddenly, I was ascribed the identity of *Muzungu mweusi* (a white-dark skinned person), a status that described me as an 'outsider within'. Research participants have different expectations from a researcher arriving as an 'outsider within' than on that arriving as a stranger. For instance, Amadiume (Amadiume 1993) describes that she encountered challenges when she as an adult returned to her fathers home village in Nigeria to conduct research. In particular, Amadiume reports on challenges due to shared cultural preferences with the research participants (Amadiume 1993). I on the other hand, only shared the assumption of common nationality and language with the research participants in the Rufiji setting. Although the perceptions and expectations from my research participants might have been of an 'outsider within', I believe that my upbringing in Sweden and in a culturally distinct environment in north-western Tanzania meant that my interpretation and

understanding of the findings was not different from that of a researcher arriving as a stranger.

Still, I acknowledged this new identity given to me as I realized that various aspects of my new identity structured how people interacted with me, types of relationships I was able to form and with whom. Which eventually may have influenced the natures of data I gathered. My background helped me to build rapport with study participant. In addition, I made efforts to integrate myself in the community by helping out in the local HIV/AIDS home-based care team, and teaching English and Science in the local secondary school. Consequently, various individuals thought I was there as a doctor, aid worker, teacher and a missionary (because I was housing in the quarter of the local Pentecostals). On most instances, I was glad that my new identities were providing me with opportunities to explain what I was doing in the setting and why I was conducting the research I was doing. Yet, understanding and accepting my presence as a researcher did not change the fact that I was ascribed the identity of *Muzungu mweusi*.

Negotiating my wealth status

As an educated Swedish/Tanzanian female living in Sweden and married to a Swedish white man, I was assumed to be wealthy by people, including my friends and family. My monthly income exceeded the yearly household income of an average Tanzanian family, and also many of my colleagues in the setting. People often asked for commodities in exchange for interviews and friendship, a wish, which I did not agree to.

People referred to my salary compared to theirs, subsequently, numerous conversations centered on economic disparities and me helping to improve their economic situation by paying for foods, drinks and helping out with necessities. Although colleagues in the field provided me with food, company and care, consequently integrating me into a network of kin, it also created feelings of obligations and responsibilities that constrained my full involvement in the community. I carefully thought about how I presented myself and visually displayed my wealth. These issues necessitated honest responses and involved the inherent inequalities in conducting research in resource poor settings. More importantly, they also offered a context for discussing with research participant the potential benefits from my research for people living in the area.

Negotiating gendered power

Social research is a process constantly mediated by gender, ethnicity, identity, and relations of power inscribed on the associations of researchers and research subjects (Agar 1996). Being a relatively well educated, wealthy (in the context of the research), married woman and novice about the culture facilitated access to particular types of knowledge and people but also felt restricted me from other research activities. The majority of my research participants in ethnographic observations are women. Still, I conducted interviews with men of various age and class; I was not able to develop interactions and rapport with men, as I was able to with women. Not because it would have seen inappropriate for me to spend

considerable time alone with men, but sometime this attempt was taken as a sexual invitation.

I first found a solution to this barrier when I invited my older brother and my aunt to live with me during fieldwork to help me with my son and take care of me (I was pregnant with my second son). My aunt, who is a sixty-two year old passionate Pentecost and herbalist, immediately developed close relationship with men and women in the community. Men in particular, sought advice on traditional *love* herbs and advice concerning their love life. During the day when I was out in the field, she was socializing in the neighbourhood. This proven to be invaluable, she provided and confirmed my information about initiation rites and *mafiga matatu*, kept me updated on local gossip, and offered invaluable insights into the gendered dynamics of men's society and love life.

My brother introduced me to the young groups of men in the community. I got the chance to sit and observe the sexual dynamics between them and women in general. I learnt how a group of men could share one woman, and sometime coerce her into group sex activity as a punishment, in case she took a man outside the group.

I attempted to arrange interviews with male religious leaders and district officials during the first period of the fieldwork. Initially, religious leaders and community elders (men and women) escaped my attempts to arrange interviews, cancelled meetings, and at one time refused to answer questions. This was not because they were reluctant to work with me or uncooperative. In matter of fact various local representatives were patient, supportive, and taught me a lot about the challenges faced in the context in relation to HIV prevention and care (I), and sexual behaviour in the context (IV). This was more related to the approach I was using, for example in the beginning I dressed in jeans and did not use the traditional shawl to cover my hair. I subsequently assumed the status expected of a Muslim female, cultured certain customs and greetings, which helped to gain acceptance from this group.

The role of researcher assistants

A considerable amount of attention is devoted to the influential role of a researcher's identity in fieldwork (Agar 1996). Less attention is conferred to research assistants and to the relationship between the study participants and the research assistant. Still research assistants facilitate research, particularly when it comes to conducting research in foreign settings. During the fieldwork of 16 months, I come to work with four different research assistants. At start of each fieldwork I held two weeks qualitative research method training with research assistants.

*Neema*¹

I had initially planned for hiring an older female research assistant from the IHI as my primary assistant. When the opportunity of working with Neema, a 22 year old female,

¹ Fabricated names (Information published after obtaining informed consent from the concerned)

Sociology student from the University of Dar es salaam presented itself, I was not sure how the process would work out in the interviews with older men. Neema grew up in the central part of Tanzania, but had moved to Dar es salaam as a teenager after that her parents had died. Her aunt was living in Rufiji and Neema usually spent weekends at her aunts' place. Neemas' high level of skill at developing a close rapport with a wide range of people, women and men, old as young out-weighed anxieties I had about her not being experienced enough for the task. Neema quickly acclimatized to my work and subsequently joined me in several ethnographic participant observations, assisted in developing the thematic interview guides (I&IV) and questionnaire (II), verbatim transcription and translated the data (I &IV).

In terms of the influence the research assistants had on the research itself; my personal relationship with Neema evolved into continued close friendship that meant that she took a greater part in this research process. Her insight on my research from the start to the end, in particular her co-participation in participant observations and the design of research instruments become influential in focusing the course of my research, one that ultimately produced a complete informed understanding of ART-related stigma (II) and dynamics around female driven multiple sexual partnerships (IV).

Lily, Greta & Amuri¹

Lily was at time a young undergraduate from the University of Dar es salaam, studying together with Neema. She grew up in Rufiji and her family still lived in the village. Both Lily and Greta were active in the local church community, Lily was active in the Pentecostal church and Greta was a Catholic.

Greta was a forty-five year old female enumerator working in the RDSS and I hired her as my research assistant following that Neema embarked on studies abroad. She had taken short college courses on qualitative research and due to the nature of her daily work she was used to the interview situation.

Women in the same age range as Greta were reluctant to engage in discussions with Greta, and similar, young women expressed worries with having Lily present in the discussions due to her stand on sexual matters. Lily however became the most qualified research assistant to keep notes during the interviews sessions and Greta became an asset during the interviews with older men.

Amuri came from the northeast of Tanzania and moved with his family to Dar es salaam at the age of fifteen. His mother got married to a local bar owner in Rufiji while Amuri was persuading his studies in Dar es salaam. Shortly after finishing the study he moved to stay with his mother and stepfather in Rufiji and immediately got a job in the RDSS. Moreover, the fact that Amuri was a popular young man among ladies, who was living and working in the same setting as the data was being collected, also posed a barrier and asset regarding the type of information participants were willing to share. For example, in one interview session with a local female participant (IV), a participant accused Amuri for having had sexual relationships with several young women from the community, on the other hand in

interviews with men Amuri did an excellent job by instinctively becoming a member of the group.

Trustworthiness

The study was developed within the explorative, inductive qualitative tradition, where study design evolved during the course of data collection. Trustworthiness in qualitative inquiry is represented by four criteria; *credibility*, *dependability*, *conformability* and *transferability* (Denzin and Lincoln 2008).

Credibility

Credibility, the evaluation of the interpretation of the data in relation to the original data collected, was assured in several ways. I used triangulation of data collection methods: focus groups, interviews and participant observations, which all contributed to thickness of the original data and credibility in the interpretations. During the data collection process the research assistants and the co-authors and supervisors contributed to constant comparisons and debriefing following data collection, which challenged interpretations. In the same way the co-authors of papers I and IV actively participated in the analysis by reading and interpreting original data individually, and hence challenging and checking conceptual interpretations.

Member check (Agar 1996, Patton 2002) were limited, because of participants' complete anonymity, follow-up on research participants from IDIs and FGDs was almost impossible. However, the collection of the data in different phases, using preliminary findings from fieldwork to design the thematic interview guides in the upcoming fieldwork, provided the possibility to re-confirm the findings. In addition, re-reading the transcripts (both in Kiswahili and English), and field notes during the analysis and writing process provided in-depth understanding for the findings. Discussions with staff members from the RDSS and with research assistants that were involved in data collection were carried out iteratively to contextualize the findings. I held de-briefing sessions with researchers conducting similar research in other parts of the SSA and those who conducting research in other field. This benefited me to get a wider understanding of the findings during the analysis.

In the section on *reflexivity* and *research assistants* I have accounted for my own and their background, which I believe assisted us in developing probing tactics for getting honest information from our informants.

Transferability

It is not possible to make inference from a qualitative study applying purposeful sampling and an explorative design. However, the detailed descriptions of the setting and data collection phase as described earlier, still allows for knowledge transfer to other similar resource poor, high HIV prevalence settings with a common culture (I & IV).

Dependability and conformability

When I first arrived in the field I was a qualified and trained qualitative researcher, however, I was not an experienced one. There were moments when I questioned my own results, particularly in relation to the understandings I drew from the data from the first interviews. Still I aimed for reliable research findings by following the guidelines and rely on my training and gained experience as the time passed. The details of the data collection process is described earlier, but in summary, purposeful sampling (Patton 2002) was used. FGDs were conducted in separate groups for women and men, and the groups were adjusted by age. Local leaders and gatekeepers initially identified research participants and eventually as I got familiar with the setting, I organized and over saw the recruitment process of participants. Men and women, young and old, with diverse social economic status were all included as informants in order to represent different perspectives. As I was living for long time in the field I was able to ensure a detailed level of good research practice during the full data collection procedure (Hennink 2007).

The diversity of experience and backgrounds between my research assistants, and me and the different research backgrounds represented by me and my co-authors and supervisors, and the use of multiple approaches in data collection helped to avoid interviewer bias and ensured conformability.

Quantitative approach (Papers II&III)

Strengths of the findings

The findings from Paper I guided the development of the questionnaire for Paper II. The well-controlled nature of data collection in a DSS setting provided the advantages of connecting socio-demographic characteristics of the participants to ART knowledge and ART-related stigma, which strengthen the findings.

Furthermore, the raw data of the age-specific mortality rates of untreated HIV-positive population came from the ALPHA network study centres in SSA (Maher et al.) prior to ART availability (Paper III). Zaba and Todd have previously reported on, and revised, the mortality patterns based on the raw data (Todd et al. 2007, Zaba et al. 2007). From this structure we could estimate the proportions of HIV-positive people that need HIV care and treatment services. The added value of this analysis is that it provides age-specific estimates of annual ART requirements and coverage at the local level that could not otherwise be estimated using current national-level estimation tools such as the Spectrum model (Somi et al. 2012c).

Within the triangulation of research and analysis methods as well as research participants this thesis was able to pinpoint where and what are the potential structural barriers for HIV prevention, care and treatment.

Limitations of the findings

One limitation of Paper II and III was the amount of missing data that was caused by various factors. The advantage with using routine data is that it provides a realistic evaluation of the empirical performance of a program. The analysis of the clinical data, however, was based on all of the data from clinic visits without distinguishing between routine scheduled visits and unscheduled visits for clinical treatment. In addition, data on clinic visits, type and number of described doses and date of transfer from pre-ART care to starting on ART had a substantial amount of missing values. This narrowed the association estimations for related indicators such as TB status and the continuation from pre-ART care to starting on ART in relation to CD4 count or WHO stage status.

However, for pre-ART care and ART coverage estimates this bias was minimized by using an average number of the people that had visited the clinic at least once during the last quarter of the year to generate the number of people receiving ART or enrolled in pre-ART care.

For the analysis in paper II, there was no stigma scale available for measure of ART-related stigma. However, this was accounted for by using LCA in the analysis to assess the level of ART knowledge and ART-related stigma. Latent classes are generally represented by Y distinct categories of a nominal latent variable X . The latent class model makes the assumption that within a latent class, the indicators are independent. Local independence is directly analogous to the assumption of uncorrelated uniqueness that is often made in factor analysis (Lanza et al. 2007).

In Paper II, the participants' HIV status was not recorded and knowledge of one's own positive status could potentially generate less stigmatizing attitudes towards people on ART. It is possible that individuals that have been tested for HIV are more likely to have knowledge of ART. Through multivariate modelling we were able to check for interactions between potential related variables, such as education and occupation status and did not find any interaction.

About 69% of the targeted population responded to the survey in Paper II. Non-response bias was minimized by performing a dropout analysis in terms of gender, age, education, and socio-economic status and by comparing survey respondents to non-respondents. This specific analysis revealed that females and individuals that were either married or cohabiting were more likely to be interviewed, but the proportional differences between females and males were minor. The study was conducted during the farming and rain seasons, which corresponded with when most men in the RDSS are temporary away in the farms and leaving the wives at home. This may explain the low response rate to the survey.

It is important to acknowledge the source of bias when using HIV prevalence estimates that are heavily influenced by movement of HIV-positive people in and out of the district, and this may lead to errors in the data in regards to incidence among uninfected individuals and deaths among those infected (Mwita et al. 2007). The national census was used to estimate the district population structure to account for the fact that the study area on ART coverage extended beyond the DSS area. We adjusted for this by using the population growth rate of 3% used from the DSS area that covers almost 50% of the district population.

Additional limitations may be due to the basic model and population assumptions or input in the model. In Paper II, LCA was used in the main analysis, LCA is highly dependent on inputs included in the model and open to multiple interpretations. The assumption made in the model in regards to the three-year survival from the need of ART to death without receiving ART is flexible (III). A different number can be applied and the proportion of HIV-positive individuals in need of treatment can be automatically recalculated. However, any number higher than three years will inevitably lead to higher ART coverage rates because a large proportion of HIV-positive individuals will need to start treatment early.

Since we did not use a validated stigma scale, nor were participants asked about their HIV status and in addition we recorded a high non-response there is a risk for information biases in Paper II. In addition, badly recorded health facility data poses (III) a substantial threat to validity of my findings. These limitations are mentioned in the discussion part of the papers.

Generalizability

The findings in Paper I raised hypotheses of HIV and ART related stigma and knowledge which were then quantitatively formally tested in Paper II. The study findings in paper I and II hence support each other and allows for transferability of results to similar contexts. The analysis in paper II is the first to provide a detailed insight into the degree of ART-related stigma in the community. Secondly, paper III provides the unique analysis of age and sex-specific access to ART among estimated HIV-positive people to need treatment. The results also form an important basis for rural district HIV care and treatment planning in resource poor settings.

CONCLUSIONS

This thesis addresses the important issue of continuing HIV-related stigma as a barrier to accessing ART care in a SSA setting. Thus we have revealed a relatively new aspect of HIV-related stigma that consists of the stigma directed specifically towards those people who use ART medications (Papers I & II). ART coverage varied by gender and age, with men and those below 25 years having the least access to ART (Paper III). It also provides a look at the social forces and mechanisms that support and constitute the female-driven multiple sexual partnerships in matrilineal descent settings (Paper IV). The conclusions of this thesis can be summarized as follows:

- There is a need to focus on skills and training for healthcare workers as a means for enhancing the trust between healthcare workers and patients (Paper I).
- The scale-up of ART does not prevent the negative attitudes towards HIV-positive individuals (Papers I & II).
- Lack of schooling and knowledge about ART results in misconceptions about ART and people on ART (Papers I & II).
- Individuals below 25 years of age and men experience insufficient access to ART (Paper III).
- There is a female-driven, male-accepted social insurance system based on multiple sexual relations (Paper IV).

IMPLICATIONS

- A focus should be placed on skills training for healthcare workers so that they are able to provide suitable and non-contradicting information and services. This will improve trust in HIV services and between healthcare workers and patients.
- Multiple sexual partnerships are deeply rooted in the community, and interventions aimed to change this practice have the risk to be interpreted as rejecting one's culture. The way forward is to find a way to accept and value the cultural dynamics within initiation rites and at same time modify their content in terms of the concepts and metaphors used to socialize the practice. The elderly women who maintain the practice must be involved as change makers.
- There is a need for scaling up structural interventions including community mobilization, custom-made interpersonal health information, and youth-friendly initiatives. These initiatives should include such practices as the use of youth counselors in mobile health clinics that would have the potential to attract this underserved age group.
- The current decentralization of HIV services can be improved by mainstreaming gender issues. Male health empowerment should be increased through mobilization of strategic allies such as male-focused community peers to attract men to scaled-up HIV services.
- The results in Paper I and II showed that participants identified people on ART as dangerous to the community. This indicates the need for work to reduce stigma, possibly through "all inclusive" intervention strategies. Such strategies should include introducing HIV prevention, care, and treatment education campaigns that correlate with an individual's level of schooling.
- The national HIV prevention, care, and treatment plan should consider the differences in gender and age in relation to uptake and access of HIV services in rural Tanzania, and should develop systems that enable populations with the greatest need to access services.

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