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**The Social Impact of HIV-Seropositivity and Antiretroviral
Treatment on Women in Tanga, Tanzania.
A Qualitative Study.**

INAUGURAL – DISSERTATION

zur Erlangung des Doktorgrades

der Medizinischen Fakultät der
Georg-August-Universität Göttingen

vorgelegt von

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aus

Göttingen

Göttingen 2017

Diese fächerübergreifende Promotion wurde unter unmittelbarer Anleitung von Herrn Prof. Dr. phil. H. Dilger am Institut für Ethnologie der Freien Universität Berlin in den Jahren 2008 – 2016 angefertigt.

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Tag der mündlichen Prüfung: 13. November 2017

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Publication as part of this dissertation:

1. **Bohle LF**, Dilger H, Groß U (2014) HIV-serostatus disclosure in the context of free antiretroviral therapy and socioeconomic dependency: Experiences among women living with HIV in Tanzania. *Afr J of AIDS Res* 13(3), 215-227, DOI: 10.2989/16085906.2014.952646

Further publications resulting from the research study:

2. **Bohle LF**: Stigmatization, Discrimination and Illness: Experiences among HIV-Seropositive Women in Tanga, Tanzania. Magisterarbeit (M.A. thesis) Göttingen 2011

&

Bohle LF: Stigmatization, Discrimination and Illness: Experiences among HIV-Seropositive Women in Tanga, Tanzania. 1. Auflage; Universitätsverlag Göttingen, Göttingen 2013

3. **Bohle LF**: HIV und Armut. Talk at the public lecture series during the winter semester 2013/2014 titled: Armut und Gesundheit. Faculty of Theology & Göttingen International Health Network (GIHN). University of Göttingen, Göttingen. 30 January 2014

&

Bohle LF: HIV im Kontext von Armut; In: Göttingen International Health Network (GIHN), Institut für Ökumenische Theologie, Tamcke M (Ed.): Armut und Gesundheit; Universitätsverlag Göttingen, Göttingen 2016, 119-130.

Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
AMO	Assistant Medical Officer
ASAP	AIDS Strategy & Action Plan
ART	Antiretroviral Therapy/Treatment
ARV	Antiretroviral
BRH	Bombo Regional Hospital
CD4	Cluster of Differentiation 4
COSTECH	Commission for Science and Technology
CTC	Care and Treatment Center
DAAD	Deutscher Akademischer Austauschdienst
GIHN	Göttingen International Health Network
GIZ	Deutsche Gesellschaft für Internationale Zusammenarbeit
GTZ	Deutsche Gesellschaft für Technische Zusammenarbeit
HBC	Home Based Care
HIV	Human Immunodeficiency Virus
HAART	Highly Active Antiretroviral Therapy
LFB	Leah-Franziska Bohle
MSF	Médecins Sans Frontières (Ärzte ohne Grenzen)
MoH	Ministry of Health (Tanzania)
NACP	National AIDS Control Programme (Tanzania)
NBS	National Bureau of Statistics (Tanzania)
NIMR	National Institute for Medical Research (Tanzania)
NNRTI	Non-Nucleoside Reverse Transcriptase Inhibitor
NRTI	Nucleoside Reverse Transcriptase Inhibitor
OCGS	Office of the Chief Government Statistician
PEPFAR	The United States President's Emergency Plan for AIDS Relief
PLWHA	People Living with HIV and AIDS
PMTCT	Prevention of Mother to Child Transmission
RNA	Ribonucleid Acid
TAC	Treatment Action Campaign
TACAIDS	Tanzanian Commission for AIDS
TAWG	Tanga AIDS Working Group
TGPSH	Tanzanian-German Programme to Support Health

TRIPS	Trade-Related Aspects of Intellectual Property Rights
UNAIDS	Joint United Nations Programme on HIV/AIDS
US\$	United States Dollar
USA	United States of America
USAID	United States Agency for International Development
VCT	Voluntary Counseling and Testing
VCTC	Voluntary Counseling and Testing Center
WHO	World Health Organization
WTO	World Trade Organization
ZAC	Zanzibar AIDS Commission (Tanzania)

“(…) if I will die it will be in Bombo, if I live it will be in Bombo. ‘till now I never went to another hospital” (Interviewee 3, Section 220).

1. Introduction

With an estimated 33 million people infected with the Human Immunodeficiency Virus (HIV) worldwide and 2.6 million newly occurred infections in the year of 2009 (Joint United Nations Programme on HIV/AIDS (UNAIDS) 2010), the infection with HIV and its Acquired Immunodeficiency Syndrome (AIDS) has developed to a pandemic and the greatest health crisis around the globe (see Figure 1). With a total of 22 million people infected in sub-Saharan Africa alone and 1.3 million AIDS-related deaths registered in 2009, HIV and AIDS has a drastic impact not only onto the lives of individuals and their families but whole communities and economies in the most affected countries.¹

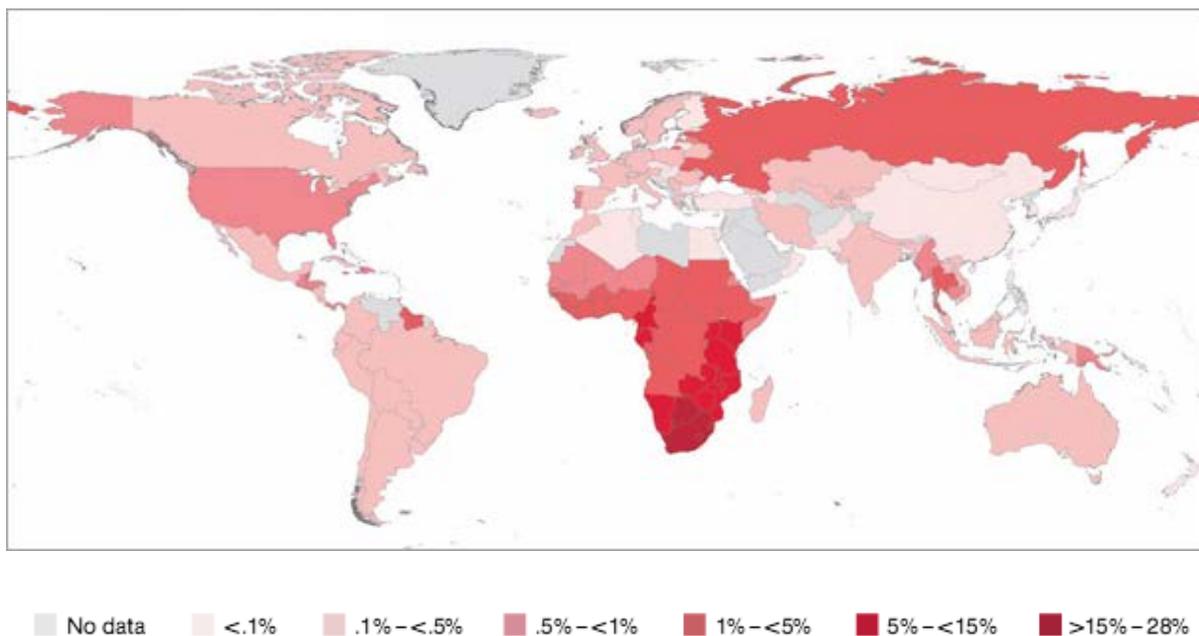


Figure 1: Global HIV-prevalence rate in 2009 (UNAIDS 2010, p. 23)

Although no cure for HIV could be invented so far, life-long highly active antiretroviral treatment (HAART) has been successfully developed for people infected. However, costs

¹ The data collection for this thesis was conducted during the year of 2008. Within this section I therefore refer to data reflecting to the overall situation at this very time span and allowing to embed the data collected into the time elapsed. In 2014 the total number of people living with HIV (all ages) worldwide had increased to 36.9 million. The HIV-prevalence rate in 2014 among adults (age 15-49) was estimated to be 0.8% (UNAIDS 2015).

for the medication remained high, with only 2% of people in low- and middle-income countries receiving antiretroviral therapy (ART) by 2001 (WHO 2002).

Access remained limited in particular due to the *Trade-Related Aspects of Intellectual Property Rights* (TRIPS) treaty, passed and adopted by countries in 1994, later forming the World Trade Organization (WTO) and ensuring patent protection and copyrights for pharmaceutical goods for a total of 20 years following development (Mutume 2001).²

Meanwhile human rights activists raised their voice, claiming access to HIV treatment a human right. Among them was the Treatment Action Campaign (TAC), founded in 1998 and developing to the leading voice in Africa, claiming access to HIV treatment for all South Africans, prioritizing patients' rights over property rights (Hardon and Dilger 2011; Treatment Action Campaign (TAC) 2015). It was when Médecins Sans Frontières (MSF) approached TAC in 1999, in order to launch a *Prevention of Mother to Child Transmission* (PMTCT) pilot project, when events started to overturn (Neumann 2011). Cipla Limited, a generic drug company from India, offered generic drugs to MSF's pilot projects for 10% of the total price of patented drugs in early 2000 (Hardon und Dilger 2011). And only a year later, in April 2001, a total of 39 countries dropped a lawsuit against the South African government for allowing to provide generic drugs to patients, turning to a milestone in the history for universal access to treatment (Mutume 2001).

With the production of generic drugs in 2001 prices dropped from 10,400 US\$ per year and person in May 2000 to 295 US\$ per year in October 2001 (MSF 2001), making antiretrovirals (ARVs) available to a wider HIV-seropositive public, in particular with a scale up of treatment availability in resource-poor settings. A further decrease in price could be observed in low-income countries, with a median price of 64 US\$ per year/person for the most common prescribed treatment regimen combination for adults (WHO 2010).

With the drastic spread of HIV and the affordability of HAART the World Health Organization declared the *3 by 5 initiative* in 2003, launching treatment to 3 million HIV-seropositive people by the end of 2005. A milestone within the target of universal access to treatment was set, leading to the following optimistic assumptions by the World Health Organization (WHO):

“Universal access to antiretroviral therapy for everyone who requires it according to medical criteria opens up ways to accelerate prevention in communities in which more people will know their HIV status – and, critically, will want to know their status. As *HIV/AIDS becomes a disease that can be both prevented and treated, attitudes will*

² Nevertheless, it was agreed on a transitional period for the implementatin of TRIPS, allowing the majority of “developing” countries to adopt the treaty the latest by the year of 2000 and “least developed” countries by the year of 2006 (Mutume 2001).

change, and denial, stigma and discrimination will rapidly be reduced. Rolling out effective HIV/AIDS treatment is the single activity that can most effectively energize and accelerate the uptake and impact of prevention. Under 3 by 5, this will occur as part of a comprehensive strategy linking treatment, prevention, care and *full social support* for people affected by HIV/AIDS. Such support is critical – both to ensure adherence to antiretroviral therapy and to reinforce prevention” (WHO 2003a, p. 6; emphasis Leah-Franziska Bohle (LFB)).

Great hopes were raised by advocates for universal access to treatment in regard to the social impact of treatment availability leading to a decrease of discrimination in connection with the infection and disease. However, chances outshined a discussion about emerging challenges caused by a life-long treatment with pills and its concomitant factors *onto* the people infected.

Few years later and with a success in treatment coverage of 5.2 million people – of an estimated total of 15 million infected people in need in low- and middle-income countries³ –, UNAIDS commented their progress within the *UNAIDS Report on the Global AIDS Epidemic 2010*, though euphoria gave way to cautious reticence:

“The question remains how quickly the response can chart a new course towards UNAIDS’ vision of zero discrimination, zero new HIV infections, and zero AIDS-related deaths through universal access to effective HIV prevention, treatment, care and support” (UNAIDS 2010, p. 7).⁴

By the end of 2008 and since the scaling up of universal access to treatment, an estimated total of 4 million people received HIV treatment in low-income countries. Among these, a total of 2.4 million people received treatment in southern and eastern Africa alone, with a 30-fold increase in people treated for HIV in sub-Saharan Africa since the end of 2003 (WHO 2008).

1.1 The Research Project

In February 2006 I was fortunate to conduct a clinical elective at the Groote Schuur Hospital in Cape Town, South Africa. Witin this elective I could assist a doctor with his

³ The WHO, the US President’s Emergency Plan for AIDS Relief (PEPFAR), the Global Fund to Fight AIDS, Tuberculosis and Malaria and further partners were joined by UNAIDS in July 2013 to launch the *Treatment 2015* initiative. The initiative aims for universal access to treatment and the coverage of 15 million people worldwide treated with ARVs until 2015 (UNAIDS 2013). A total of an estimated 9.7 million people in low- and middle-income countries received ART by December 2013. With an estimated 28.6 million people eligible for treatment in 2013, this represents only 34% receiving needed treatment, showing that increase of treatment – in particular in low- and middle-income countries – is more than ever needed (UNAIDS 2013).

⁴ Until now, the elimination of “HIV-related stigma, discrimination, punitive laws and practices” (UNAIDS 2013, p. 1/p. 84-97) remains one of the ten most primary concerns as indicated in the recent *UNAIDS Report on the Global AIDS Epidemic 2013*.

HIV-consultations at the Nolungile Hospital in the township of Khayelitsha – the hospital where MSF first launched its ART pilot project in the year of 2000.

While assisting during the consultations I came across the manifold challenges caused by access to antiretroviral treatment. In particular, HIV-seropositive women reported of the difficulties of avoiding involuntary disclosure and hiding the monthly ration of medication in their township houses, which were often shared by many people and with very limited privacy. These profound experiences with HIV-seropositive women in South Africa led to the idea of focusing on the impact of ART onto the lives of women infected with HIV and enrolled on antiretroviral treatment in Tanzania.

The clinical-based qualitative research project was conducted in the United Republic of Tanzania⁵ in the year of 2008. At the time, Tanzania had an estimated HIV prevalence rate among adults of 6.2% (UNAIDS 2008), with a total of approximately 1.4 million people infected (PEPFAR 2012). Within the research area of Tanga Region, prevalence rate between 4.5% and 6.9% fairly equaled the national rate (UNAIDS 2008) with significantly more women affected (UNAIDS 2010).

With the implementation of access to free antiretroviral treatment in 2004, the number of people enrolled on treatment increased countrywide from 2,000 people in the first year of free treatment availability (Tanzanian Commission for AIDS (TACAIDS) 2009) to nearly 200,000 by 2009 (UNAIDS 2010).⁶ At the time of research conduction a total of 6,300 HIV-seropositive patients – with the overall majority being female – were officially registered at the Care and Treatment Center (CTC) at the public Bombo Regional Hospital in Tanga City, serving as research location.

With the availability of free ART and an expected change in disease perception from a deadly to a chronic and treatable disease, a major reduction in discriminating attitudes towards HIV was widely anticipated as outlined above – hence, possibly resulting in a change in disclosure rates and patterns. This multi-methodological research study focused on the process of verbal self-disclosure in an era of treatment availability, giving voice to

⁵ To ensure readability solely the term *Tanzania* is used when referring to the *United Republic of Tanzania*.

⁶ Available antiretroviral medications were the combination of either two nucleoside reverse transcriptase inhibitors (NRTIs) and one non-nucleoside reverse transcriptase inhibitor (NNRTI) or two nucleoside reverse transcriptase inhibitors (NRTIs) and one protease inhibitor. First-line antiretroviral medications in use were Triomune 30 or Combivir combined with either Nevirapine or Efavirenz. Second-line medication offered were Didanosine in combination with Abacavir or Lopinavir/Ritonavir (Kaletra). No additional ARVs were available at that time.

the people infected and shedding light onto the social impact of ART on their lives in regard to chances and challenges caused by treatment availability.

In particular, this study focused on reasons for disclosure and non-disclosure, the choice of the first person and the following significant others to inform or intentionally not inform and reactions to disclosure. Furthermore we have asked our interviewees about their (voluntary) counseling and testing (VCT) experiences, reasons for testing, satisfaction of staff performance at CTC, their suspected mode of transmission, condom use, experiences with traditional healers and ART. Furthermore we collected detailed socio-demographic and medical data.

During research conduction and with final data analysis the following core topics emerged: 1) reasons for disclosure and non-disclosure and the choice of significant others (not) to inform, 2) reactions to disclosure experienced, 3) the perception of HIV and AIDS, as well as 4) adherence to ART among HIV-seropositive women enrolled on treatment. With the first topic dealt with in the publication related to this thesis, we would like to focus on the latter (2-4) and briefly present further results concerning reactions to disclosure, the perception of HIV and AIDS and experiences made with ART reported by our interviewees in regard to the social impact of ART on the lives of infected.

1.2 Publication of Results

Due to a wealth of data collected, the data and findings were divided and used for several publications – specifically the Magisterarbeit (i.e. M.A. thesis) and the medical doctoral dissertation – as listed above.

The M.A. thesis is titled „Stigmatization, discrimination and illness. Experiences among HIV-seropositive women in Tanga, Tanzania“ and was submitted at the Faculty of Social Sciences on 3 August 2011. It was published as a book at the Göttinger Universitätsverlag at the end of 2013 with the identical title.

The medical dissertation submitted is publication based. The publication is titled „HIV-serostatus disclosure in the context of free antiretroviral therapy and socio-economic dependency: experiences among women living with HIV in Tanzania“ and was published in the African Journal of AIDS Research“ on 12 November 2014.

Although the publications are based on the same datasets, the topics and research question(s) investigated, the amount of data, the methodological and analytical approach as

well as the literature cited, differ greatly.⁷ The M.A. thesis focuses on stigmatization and discrimination as a social phenomenon, as well as illness (i.e. a subjective experience) versus disease (i.e. a biomedical terminology) in relation to HIV and is embedded in a medical-anthropological context. In contrast, the medical dissertation thesis focuses on disclosure of the HIV-seropositive status including related sub-topics. Here, (non-)disclosure is approached from a Public Health angle and social, emotional and economic reasons for disclosure and non-disclosure are discussed.

The M.A. thesis uses an ethnographic approach, presenting a selection of six interviews in depth. Here mainly qualitative data (through a biographical approach) and direct citations are used and supported by participant observation. Quantitative socio-demographic data of the overall sample is presented to justify the selection of the six interviewees presented in detail. The medical dissertation thesis however, presents the quantitative data in detail and presents the full set of qualitative data mainly through quantification and few direct citations.

Overall 149 different bibliographical sources were referred to in the M.A. thesis, with a specific focus on stigmatization and discrimination in relation to HIV, and in contrast to 57 literature sources cited in the publication of the medical doctoral dissertation, with a specific emphasis on disclosure. Overall, a total of nine publications were identical in the M.A. thesis and medical doctoral dissertation. These sources however refer to country data and the methodology with two exceptions: one book published by Dilger in 2005 titled “Leben mit Aids“, as well as one article, focusing on stigmatization as well as the disclosure of the HIV-seropositive status and attitudes towards the treatment of HIV by Zou et al. (2009).

1.3 A Literature Review of the Core Topics

The anticipated change in disease perception with the implementation of ART has only been marginally explored. According to the *Tanzania HIV/AIDS and Malaria Indicator Survey 2007-08*, which collected data from October 2007 to February 2008 and prior to our study commencement (March 2008), levels of discrimination among the Tanzanian communities remain high (TACAIDS et al. 2008). However, Roura et al. showed a unique development of the perception of HIV and AIDS as being a *normal disease* among HIV-seropositive patients from an HIV-department receiving ART (Roura et al. 2009).

With an anticipated reconceptualization of HIV and AIDS coming along with ART availability, a change in reactions by significant others disclosed to could also be expected.

⁷ For a detailed overview on the methodological approach and data analysis related to the publications, please view Chapter 3.

Before the advent of HAART, reactions to HIV-serostatus disclosure among women have been researched in the United States of America (USA), Western Europe, sub-Saharan Africa and Asia (Keogh et al. 1994; Simoni et al. 1995; Gielen et al. 1997; Medley et al. 2004; WHO 2003b), though only few in number and with a strong focus on reactions by the women's partners only. Within the two literature reviews available, reactions resembled and ranged from positive outcomes, such as encouragement and kindness (Medley et al. 2004), to increased support and acceptance (WHO 2003b). Negative outcomes experienced were blame and stigma, abandonment, anger, separation and violence (Medley et al. 2004; WHO 2003b). However, violence was rarely mentioned, with a higher degree in the USA and Western Europe (WHO 2003b). After the access to treatment availability outcomes of disclosure have again been marginally researched and with a regional focus on sub-Saharan Africa (Deribe et al. 2008; Gari et al. 2010).

Within the United Republic of Tanzania very few authors have dealt with the actual outcome of disclosure before the availability of ART (Kilewo et al. 2001; Maman et al. 2003; Dilger 2005), with Kilewo et al. and Maman et al. addressing reactions by the sexual partners of HIV-seropositive women only. Reactions by partners were mostly positive, with only few HIV-seropositive women experiencing blame, assault, violence or separation (Kilewo et al. 2001; Maman et al. 2003). However, one individual interviewed by Dilger (2005) reported of blame, denial of support and withdrawal of his family. Among the few studies on this topic conducted in Tanzania since the availability of antiretroviral treatment (Greeff et al. 2008; Lugalla et al. 2008; de Klerk 2012; Moyer 2012; Bohle 2013; Bohle et al. 2014) positive and negative outcomes were reported, ranging from accusation, denial, animosity, emotional and physical withdrawal, fury and blame, psychological abuse, separation and exclusion amongst others (Greeff et al. 2008; Lugalla et al. 2008; Moyer 2012; Bohle 2013). However, studies differed greatly concerning location, research question, study sample and methodology.

Within the studies conducted by Greeff et al. (2008) and Lugalla et al. (2008) in Tanzania, ART was no mandatory selection criteria, while both recruited patients from support groups. Here it can be expected that people visiting a support group, having disclosed to its members and deliberately confronting themselves with their infection, are also dealing more openly with their disease, hence leading to a bias in results.

Prior to the implementation of universal access to treatment, influential opponents, such as Andrew Natsios, at the time administrator of the United States Agency for International Development (USAID), voiced great doubts with the ability of "Africans" to adhere to

complex treatment regimens in resource-poor settings (Donnelly 2001). Optimal adherence to HAART – ideally of 95% or higher – is of great importance (Paterson et al. 2002), not only to secure the stabilization of the health condition of the infected and to minimize the viral load and risk for infection of others, but to also avoid possible development of resistances in particular with regard to only first- and second-line treatment availability as the case in the majority of low-income countries until now.

Adherence rates have been widely researched since the availability of HAART. The inability of adhering to antiretroviral therapy by people infected in low-income countries, as widely claimed by opponents of universal access, did not prove true. In the contrary, much greater adherence rates could be shown in resource-poor settings, compared to those of industrialized countries (Ivers et al. 2005; Mills et al. 2006a; Mills et al. 2006b; Attaran 2007; Ware et al. 2009a), leading to the urgent questions of why do people have such higher adherence rates and how do people perceive and respond to ART?

In the United Republic of Tanzania, numerous studies have been published, focusing on influencing factors on adherence rates since the availability of HAART. While several studies have dealt with obstacles to adherence (WHO 2006; Hardon et al. 2007; Ramadhani et al. 2007; Dlamini et al. 2009; Irunde et al. 2009; Makoae et al. 2009; Watt et al. 2010; Baltazary et al. 2011; Mattes 2011; Lyimo et al. 2012; Lyimo et al. 2014; Thielman et al. 2014), few have presented results on reasons supporting adherence to ART (Watt et al. 2009; Ware et al. 2009b; Watt et al. 2010; Lyimo et al. 2012). However, the social impact and perception towards antiretroviral treatment among HIV-seropositive people in Tanzania remain mostly unknown while qualitative in-depth studies are needed.

The summary presented below provides a brief overview of the research conducted in Tanzania. First, and for a better understanding of the location, the research setting will be described. Second, and within the chapter of methodology, insight is given into the overall structure of the research study, including the study participants, the recruitment process, the protection of human participants and the methodological approach, as well as the data analysis in use.

Following, selected data on the main topics of interest evolved during interviewing will be presented, focusing on reactions to disclosure, the reconceptualization of HIV among our interviewees, reasons and strategies of ART adherence and perception and impact of HAART on the lives of our interviewees. Finally I would like to discuss the results presented and comprise with a conclusion and a way forward.

2. Research Setting

The Care and Treatment Center located at the Bombo Regional Hospital (BRH) in Tanga, Tanzania, was chosen as research location. The BRH is the main and leading University affiliated hospital in Tanga Region, providing biomedical treatment to a population of more than 242,000 people in Tanga District alone (National Bureau of Statistics and Ministry of Planning, Economy and Empowerment 2006). The CTC, inaugurated in June 2006 and supported by several international and national stakeholders,⁸ served the needs of 6,300 registered HIV-seropositive patients in 2008, with the majority (69%) being female and more than half enrolled on antiretroviral treatment.⁹ Hence, the department was daily crowded with people, waiting for testing, medical check-ups, the commencement of ART, adherence classes or the prescription of further medication. At the time the department itself was incorporated into the hospital and included a Voluntary Counseling and Testing Center (VCTC), several offices for medical consultations, a laboratory, a pharmacy, as well as rooms for regular education sessions.



Figure 3: A young woman being tested for HIV at the VCTC at Bombo Regional Hospital (LFB, 2008)



Figure 2: An HIV rapid test conducted by the nurse at the VCTC at Bombo Regional Hospital (LFB, 2008)

⁸ For further information please see Mattes (2011).

⁹ According to an informal interview in October 2013 with staff from the CTC at BRH, over 10,000 patients were registered at the newly built HIV clinic located on the hospital compound.

Prior to ART commencement patients had to attend three mandatory adherence classes, during which they received information on the disease, such as possible modes of transmission, as well as the medication, dosage taking, symptoms, side effects, and optimal nutrition.¹⁰ Adherence rates could only be indirectly measured, recording pill counts conducted by the pharmacists during refill of medication bottles, questioning and self-report of the patients in case of remaining pills and a CD4 count check approximately every 3-6 months. However, plasma HIV-1 RNA levels could not be measured.

The staff at the CTC included several Assistant Medical Officers (AMOs)¹¹, specially trained nurses, pharmacists, data clerks and volunteers.

The Tanga AIDS Working Group (TAWG), a non-governmental organization inaugurated as early as 1992, is also located at the hospital compound and widely known for its longtime care and support of people living with HIV and AIDS (PLWHA). It not only offers VCT and HIV-testing at multiple testing centers in Tanga City, but herbal medicine to HIV-seropositive patients not yet enrolled on ART due to a high CD4 count, as well as Home Based Care (HBC). It also provides trainings for traditional healers and works in close collaboration with the BRH and traditional healers in the region (TAWG 2010; Personal interview with Dr. Firimina Mberesero, founder of TAWG, Tanga City, 08.08.2008).

Besides its biomedical treatment options, Tanga District remains famous for the power of its traditional healers (*mganga kwa kienyeji*), their herbal medicine (*dawa za mitishamba*) and spiritual powers (*kwa ramli*)¹², with people from all over the country coming to Tanga seeking cure (and perceived) justice.¹³

¹⁰ For further information concerning *adherence classes* at the department please see Mattes (2011).

¹¹ Assistant Medical Officers (AMOs) have finished medical studies at university and have undergone special health care courses being in the position between a Clinical Officer and a Medical Officer, which can be compared to the tasks of a resident. They are able to provide curative and preventive services, and are eligible to conduct minor operations (Pemba 2008).

¹² In brackets are the expressions in Kiswahili, together with English, the official languages in Tanzania.

¹³ According to the National Bureau of Statistics (NBS) a total of 15% of the total Tanzanian population on the mainland visit traditional healers, among these about 5.5% of urban residency (2002). For further information on spirit possession at the Swahili coast please see Giles (1989) with results based on three years of fieldwork from 1982-1984 for her PhD thesis. For further information on healing in Tanzania please see Langwick (2011), and for information particular on Tanga, please see the book written by Mackenrodt entitled *Swahili Spirit Possession and Islamic Healing in Contemporary Tanzania* (2011).

3. Methodology

3.1 Research Design, Ethical Clearance and Research Team

For this clinic-based research study, a multi-methodological approach was chosen, including the conduction of participant observation at the CTC and during interviews with patients, questionnaires and semi-structured guideline interviews with HIV-seropositive women enrolled at the CTC. Further, semi-structured guideline interviews with hospital staff, the founder of the TAWG and the Regional AIDS Control Coordinator of Tanga Region were undertaken, as well as informal interviews during the research phase.

The study received ethical clearance from the ethical committee of Göttingen University and the National Institute for Medical Research in Tanzania (NIMR), as well as research permission from the Commission of Science and Technology (COSTECH) in Tanzania.

The research team consisted of two female Tanzanian interviewers with no prior employment at the hospital, fluent in English and Kiswahili, and two independent translators. Two days per week one interviewer each conducted interviews with HIV-seropositive women, while at the same time the other interviewer and the principal investigator (LFB) conducted participant observation at the CTC/VCTC.

3.2 Study Participants and Recruitment Process

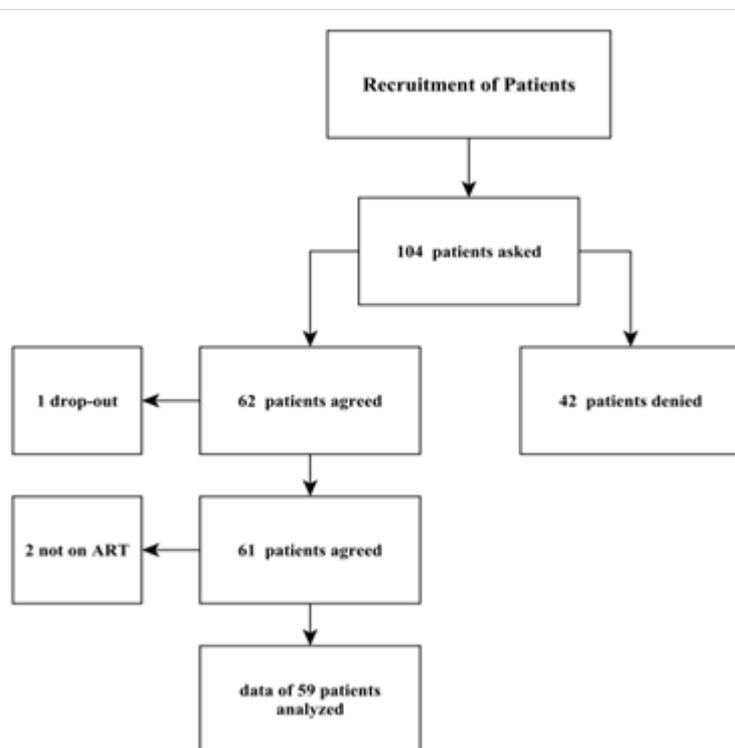


Figure 4: Recruitment of patients

Exclusively female patients were recruited by the AMOs, fulfilling the recruitment rules of being over 18 years of age, registered at the CTC, tested positive for HIV the earliest at the last visit of the CTC, being in a stable health condition to undergo the interview and prior to study commencement having provided written or finger-ink printed consent. A total of 104 female women were asked for participation of which 62 (59.6%) agreed. With one

dropout prior to study commencement, a total of 61 women finally participated in the study, of whom 59 were enrolled on ART.

For the publication attached and results presented within the chapters 4.2.3 and 4.2.4, only patients on ART were included in the data analysis (see Figure 4), while remaining results presented here include results from all 61 women interviewed.

Following recruitment and verbal consent of participation, women were elucidated of the study in Kiswahili by the interviewer, were asked to give signed/finger-ink printed consent and received a copy of the signed clearance and consent form in Kiswahili prior to study commencement.

3.3 Questionnaires for HIV-Seropositive Women

A short questionnaire conducted by the AMO, using health-related information from the patient's file taking approximately two minutes, followed a further pre-tested interviewer administered questionnaire in Kiswahili, containing a total of 34 questions and read out by the interviewer, taking approximately ten minutes. Questions focused on socio-demographic data, self-disclosure and adherence to ART and were adapted to the Tanzania setting.¹⁴

3.4 Ethnographic Qualitative Methods

Following the questionnaires, a pre-tested standardized open-ended and audio-recorded interview followed, expanding upon the questions answered within the questionnaire.

Furthermore, emphasis was placed on participant observation during the interview sessions and conducted by the principal investigator. Aim was to document the patient's look, facial expression and behavior during the interview session and the interaction between the interviewer and the interviewee, providing further information on their life and experience with the disease. Furthermore participant observation was conducted at the department by the research team, while numerous informal interviews and expert interviews were held.

3.5 Processing of Data Material

Interviews were directly transliterated after the interview session, using the open source audio-editor software Audacity 1.2.6a and the audio-transliteration software F4 for Microsoft Word. For transliteration slightly modified transcription rules designed by Kallmeyer and Schütze (1976; cit. in Mayring 1993) were in use. Two independent translators, fluent in both languages, translated the transliterated interviews from Kiswahili into English. Finally, the

¹⁴ The development of the questionnaire was influenced by studies focusing on disclosure and conducted in Tanzania in the past (e.g. Lie and Biswalo 1996), as well as inspired by Braun (2006) as preconditions in Tanzania – such as the school system – differ tremendously while *The Allgemeine Bevölkerungsumfrage der Sozialwissenschaften* (GESIS 2011; Eirnbter and Jacob 2000) could therefore not serve as a basis.

translation was proofread to secure validity of the translation and content discussed on a regular basis with the interviewers.

The participant observation was simultaneously paper-documented and typed on the same day whenever possible and as suggested by Rosenthal (2008), focusing on observation without valuation.

3.6 Data Analysis

For further characterization of the women interviewed, questionnaires containing socio-demographic and medical data were analyzed and frequencies calculated using SPSS 15.0 for Windows, with all figures rounded up to two decimal places.

After general revision of the 61 interviews conducted with patients, content analysis was used for coding of the interviews and as defined by Flick (2007). After definition of main categories (= codes), such as *self-disclosure*, *reactions to disclosure* or *ART adherence*, further sub-categories were established, in particular by creating so called *in-vivo codes*, using terms verbally directly extracted from the interviews (Kuckartz 2005). Sub-codes were then deducted from main codes, such as the differentiation between different forms of

reactions to disclosure. Finally, information deducted from the interviews were categorized and paraphrased “...through selection, deleting or bundling of codes” (Lissmann 2001, p. 71).

For coding, the text analysis program MAXQDA Version 2 for Windows XP was used, offering an overview of data collected and simplifying transfer from coded material to SPSS.

Before final coding of the interviews, inter-rater reliability was ensured with a cross-check conducted by an independent coder, coding >10% of the interview material, as recommended by Mayring (2000).

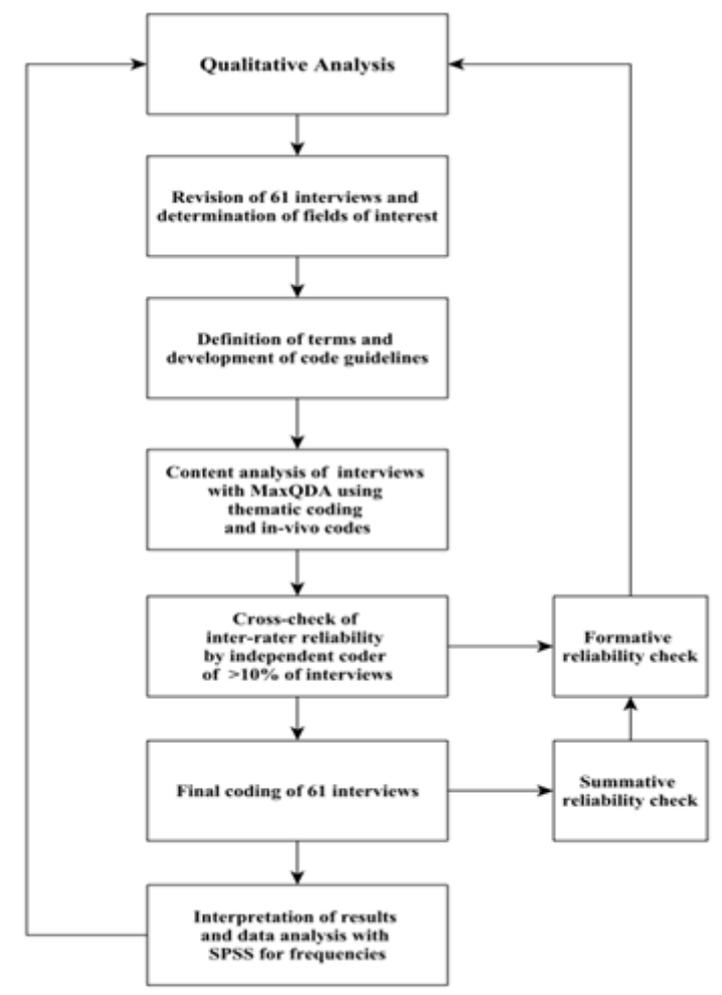


Figure 5: Qualitative analysis of interviews (based on Mayring (2000, p. 4) and modified by LFB)

A discussion of the results with the independent coder and optimization of the code guideline in use followed. The final code guideline was used for a new and overall coding of all 61 patient interviews (see Figure 3). Coded interview material was analyzed and manually extracted, while for the publication attached data was transferred to SPSS for analyzation of frequencies of statements, allowing for the interpretation of the impact of statements given.

Furthermore, data from the participant observation, relevant for the results presented here were manually extracted in order to provide further detailed information on the research setting, the circumstances and the women interviewed.

Overall transliterated interview material amounts to more than 1,000 pages of data, with an additional 300 pages of documented participant observation.

3.7 Methodological Approach of the M.A. Thesis in Comparison to the Medical Doctoral Thesis

The above section refers to the methodological approach of the medical doctoral thesis and its publication in the African Journal of AIDS Research.

Although the data analyzed and used for the publications derives from the same output data source, the thematic focus, methodological approach used for the M.A. thesis differs greatly in regard to the thematic topic, selection of data and analysis of data.

The M.A. thesis focused on six selected interviews deriving from the output data while an ethnographic approach (through the use of qualitative and biographical data) was used. The qualitative data was supplemented by the analysis of five socio-demographic variables¹⁵ originating from the 61 quantitative data sets (questionnaires only). Two diagrams¹⁶ and three tables¹⁷ present graphically the six interviews selected in clear distinction to the overall sample (n=61) in order to defend the selection process of the six interviewees portrayed. Six selected interviews were analyzed in detail using a qualitative approach and numerous direct citations embedded into participant observation were presented.

For the medical dissertation a multiple-methodological approach was used, analyzing all 59 interviews and questionnaires with HIV-seropositive women on ART. The quantitative data of all 61 women interviewed is presented, including all socio-demographic variables collected, the time since HIV-diagnosis, the time since ART commencement, receiving of counseling and adherence counseling and full, partial and non-disclosure in detail. Further, 59

¹⁵ The variables refer to age ("mean" only), religion ("frequency" only), education and ethnic origin (both in detail).

¹⁶ Focusing on the religious affiliation and education.

¹⁷ Focusing on education, religion and ethnic origin.

interviews were analyzed using a quantitative and qualitative approach and through the quantification of qualitative findings.

The analysis of the data was conducted separately and independently for both publications and also due to the different thematic foci. The analysis for the medical dissertation is described in detail above.

In the frame of the M.A. thesis a total of 10 randomly selected interviews from the overall data set of 61 interviews were coded, in regard to the previously defined terms including “discrimination”, “stigmatization”, “illness” and “disease” and a code tree built. In-vivo codes, fact- and sub-codes were built. Following a total of 10% of the coded interview material was re-coded by an independent person to cross-check for inter-rater reliability. The code trees were compared and updated depending on the outcome of the two coding processes. Following the newly developed code tree was used and all 61 interviews coded again. In another step, a total of six interviews were chosen out of the pool of 61 interviews. The notes of the participant observation taken during these six interviews were also selected. As outlined in the M.A. thesis, “...(it) concentrates on the topic of discrimination and stigmatization in the context of illness and disease the topic of disclosure was not analyzed here in particular although it was mentioned within the results where applicable and necessary” (Bohle 2011, p. 50; Bohle 2013, p. 61).

4. Results

4.1 Results of the Questionnaire – Quantitative Data

Within our study sample the age of women interviewed ranged between 22 years and 63 years, with a mean age of 38.8 years and with a total of 44 women (74.6%) being of Muslim religion. Interviewees belonged to 20 different ethnic groups, with the Wasambaa (11 women, 18.6%), Wadigo (10, 16.9%) and Wabondei (7, 11.9%) – originating in Tanga Region – representing the majority.

The majority of women attended primary school in the past (n=46, 78.0% respectively), with again the majority working in the informal sector (n=27, 45.8%) or being unemployed and responsible for the household and the education of (their) child(ren) (n=18, 30.5%), with a mean monthly income of their household comprising of 35 Euro (52US\$). The mean time of diagnosis among our interviewees was 1.9 years, with a maximum of 10.9 years and a minimum of 20 days.¹⁸ A total of 45 women could indicate the exact day of treatment commencement with a mean treatment time of 1.2 years.

Prior to study commencement, an informal survey focusing on the adherence to ART among patients at the CTC with 14 members of the hospital staff at the HIV-department was conducted. The staff members were asked to voluntarily estimate the percentages of patients taking their ARVs regularly, and patients taking them irregularly. On average it was estimated that 80% of the patients took their medication regularly (max. 95%, min. 65%), with 20% taking them irregularly (max. 30%, min. 5%).¹⁹

According to our findings, three interviewed women (5.2%) reported of having missed a dose within the last seven days, while 56 women (94.9%) have indicated of not having missed a dose within the last week prior to interviewing. When asked about overall adherence since the start of ART commencement, a total of 21 women (35.6%) told us of having missed at least one dosis since the start of treatment, while 37 women (62.7%) have not missed a dosis at all, with the answer missing of one participant.

4.2 Interview Results – Qualitative Data

Following, results of the 61 interviews conducted with female HIV-seropositive patients enrolled at the CTC concerning 1) the reactions to disclosure, 2) the perception of HIV and AIDS in an era of treatment availability, 3) reasons and strategies for ART adherence and 4)

¹⁸ For further detailed socio-demographic and medical information on the study sample, please see the publication attached.

¹⁹ Regular intake was defined as taking them on a regular basis, without missing a single dosis.

the perception and impact of HAART onto the lives of infected will be briefly presented. To ensure fluency in reading, transliteration notes were omitted within citations presented below.

4.2.1 Reactions to Self-Disclosure

Focusing on *reactions to disclosure*, three main categories evolved during content analysis and within statements given: First, women reported of experiences made, *positively* influencing their lives (58 women, 95.1%), such as receiving support. Second, interviewees mentioned experiences made, *negatively* influencing their lives (36 women, 59.0%), such as discrimination. Further experiences mentioned not suiting the two above categories were coded within the category of *other reactions* (32 women, 52.5% respectively).

Positive reactions: Within the category of positive experiences, six major different reactions could be identified. Among these, seven different types of support as a reaction to verbal self-disclosure were mentioned regularly by a total of 51 women (83.6%). One of our interviewees described her experiences resulting in disclosure the following:

“They just took it as normal and they assist me when I have problems. (...) There is one aunt of mine even if I tell her today I have this problem she assists me (...). She is the one who helps me very much” (Interviewee 15, Section 88).²⁰

When one of the women interviewed disclosed to her grown-up children, they replied acceptingly “Mama (it is) ok, it [i.e. HIV] is a worldwide trouble!” (Interviewee 5, Section 69).

In particular, encouragement as a result of disclosure, was explicitly mentioned by 29 women (47.5%). As one woman, who informed immediate members of her family of origin, told us:

“I guess they, they had suspicion before [i.e. of me being infected with HIV]. (...) but they encouraged me and until now they are encouraging me” (Interviewee 06, Section 58).

During the interviews women told us that they were comforted by people having disclosed to, saying that HIV has become a *normal* disease (9 women, 14.8%) and should therefore be accepted (31 women, 50.8%). One of our interviewees disclosed to her maternal uncle (*mjomba*), informing him about problems she was suffering from due to infection and he replied the following:

²⁰ Within this thesis direct citations contain round brackets (...) indicating that text was omitted, round brackets with text, supplementing the sentence for a better understanding and square brackets, directly relating to a specific word or wording in the text for clarification.

“It is normal my daughter, do not be worried. These are things which are seen among all of the people’. Then I found them normal, because when I come here at the hospital usually I find a lot of the people [i.e. at the CTC being infected with HIV] and I get hope” (Interviewee 11, Section 44).

Although the majority of the women experienced some sort of discrimination, 22 women (36.1%) also explicitly told us, that they were not discriminated by the people they have disclosed to, as mentioned by this interviewee:

“My relatives received me just well. They did not discriminate me to this minute. They refused even (me being) in the kitchen. I do not cook now. ‘Our fellow is sick, leave her!’ (they say). Honestly, I thank them!” (Interviewee 20, Section 89).

Apart from support²¹ and encouragement, 34 women (55.7%) mentioned receiving advice from others following verbal self-disclosure, with only one woman directly mentioned empathy (1.6%).

Negative reactions: Among this category, eight major different negative reactions were identified among the interviews conducted and analyzed. Within the category of emotions, a total of four different emotions experienced were reported by a total of 22 women (36.1%). Among them sadness was a common expression among significant others informed of a woman’s HIV-seropositive status (18 women, 29.5%). As one of our interviewees told us:

“(…) they were sad. Many have cried a lot for me, many have cried a lot until they advised me ‘Thank God, it [i.e. HIV] is a normal thing. Do not think too much!’” (Interviewee 42, Section 158).

Five women (8.2%) also experienced denial, as one of our interviewees described the reaction of her husband: “Until now my husband does not believe that I am infected, do you understand? But we talk and laugh (…)” (Interviewee 3, Section 234).

Further reactions to disclosure depicted by the interviewees were anger (4 women, 6.6%), accusation (4 women, 6.6%), separation (1 woman, 1.6%) and the need to move out of the house (8 women, 13.1%). One of our interviewees described the reaction after disclosure by her mother and the younger sister of her mother (*mama mdogo*) the following:

“They were angry. (...) They asked where did I get the problems [i.e. being HIV-seropositive] from. Then they calmed down“ (Interviewee 4, Section 131 and 133).

Furthermore one interviewee (1.6%) experienced her husband demanding for a proof of being infected, while a total of six women (9.8%) were commanded not to disclose further, as stated by one woman: “I was unhappy. The fact that my husband told me I should not tell

²¹ Within the interviews women differentiated between general support, health support, economic support, emotional support or any other type of support.

anybody gave me a headache” (Interviewee 3, Section 218) and “I was afraid of my husband because he didn’t want anybody to know” (Interviewee 3, Section 205).

Additionally, 11 women (18.0%) reported of various forms of massive discrimination directly in connection with revealing their HIV-seropositive status, in particular by non-relatives, such as neighbors, their partner’s family or their partners. As one of the women told us: “(...) my step-mother and me we were not getting along. She didn’t want me. She was discriminating me a lot“ (Interviewee 27, Section 38).

Other reactions: Furthermore, seven different reactions could be identified, not suiting the two categories above, mentioned by 32 women (52.2%). People were surprised (2 women, 3.3%) or felt frail (3 women, 4.9%). As one interviewee said: “I guess they, they had suspicion before [i.e. of me being infected with HIV]. They were shocked, they were shocked to some instance (...)” (Interviewee 06, Section 58).

Others went testing themselves (14 women, 23.0%) or asked for advice (2 women, 3.3%), while again others answered that the diagnosis could not be changed (6 women, 9.8%), as described by one of our interviewees when disclosing to her son who answered: “(...) ‘Mom it has happened already what should we do? It is a normal disease (which can happen) to every human being!’“ (Interviewee 45, Section 158). Again others experienced no reaction at all (2 women, 3.3%) as one of the women interviewed described: “Well, when I told my mother she did not say anything, she just kept quiet“ (Interviewee 60, Section 95).

4.2.2 The Conceptualization of HIV and AIDS among HIV-Seropositive Women at the CTC

During the interviews conducted the term normal (*kawaida*) was significantly frequently used (347 times) by our interviewees in connection with HIV and AIDS, with 10 different categories evolving in the context of reactions to disclosure. One of our interviewees described the reactions by her relatives after disclosure the following:

“They took it as it is. They told me not to think about it all the time, not to lose hope, because it is a *normal thing*. Anyone may get HIV. I should not get worried and lose hope. I then accepted their advice” (Interviewee 10, Section 29; emphasis LFB).

However, being HIV-seropositive was not only interpreted as *being normal* (reported by 29 women, 47.5%) by immediate family members of origin chosen for self-disclosure, but in particular by the patients themselves (31 women, 50.8%). As one of our interviewees answered, when asked about her experienced reactions to disclosure: “(...) the problem is that there is no cure for this [i.e. disease]. (...) but right now it [i.e. being infected with HIV] has become *normal*” (Interviewee 9, Section 97-98; emphasis LFB). And another interviewee

stated: “I now see it [i.e. being HIV-seropositive] just *normal*. HIV/AIDS is a *normal problem*” (Interviewee 12, Section 20; emphasis LFB).

Reasons for these assumptions were manifold. *First*, a total of seven interviewees (11.5%) said that the destiny of becoming infected with HIV could affect anybody, hence leading to *normality*, as argued by one of the woman: “I *felt normal* because I knew there is such an epidemic and this disaster could happen to anybody else” (Interviewee 5, section 4; emphasis LFB). *Second*, the high number of people infected led to the assumption of HIV and AIDS being *normal* (11 women, 18.0%).

One of our interviewees described her disease perception before receiving adherence classes the following: “(...) I knew when you get that problem [i.e. HIV and AIDS] perhaps that’s the end of life” (Interviewee 12, Section 17). However, after attending the classes at the CTC she told us that she realized “(...) a lot of people are infected. To me these are like *normal things* nowadays” (Interviewee 11, Section 8; emphasis LFB). And another woman told us:

“That sister of mine also said it is only that some of us have not get tested but we are all infected, the whole of Tanga! But it is only that we have not gone to get tested, but we are infected!” (Interviewee 34, Section 131).

Third, the high number of people infected with HIV again led to comparisons with often occurring diseases as reported by one woman as a direct reaction to disclosure. She told us: “(...) this [i.e. HIV] is a *normal thing*, it can occur to anybody. Let us say it is like Malaria for people now” (Interviewee 34, Section 131; emphasis LFB). And *fourth*, although HIV was known as being incurable among our interviewees, women now had the possibility to actually treat their disease with medication, leading to a *normalization* and change in perception of the disease as indicated by 6 women (9.8%).

4.2.3 Reasons and Strategies to ART Adherence

Throughout the literature no universal definition for adherence to ART exists and several methods for measurement are in use. Overall, studies measuring the outcome of adherence are focusing on missed doses, exceeding pill taking and/or the timing of dosage taking. In general, measurement is conducted by self-report and missed doses over a certain time period, pill count, refill records, or proportion measurement through electronic monitoring advice (Simoni et al. 2003) or plasma levels of HIV-1 ribonucleic acid (RNA) (equaling the viral load level).

The *National Guidelines for the Clinical Management of HIV/AIDS*, distributed to the AMOs and developed by the National AIDS Control Programme (NACP) on behalf of the Tanzanian Ministry of Health (MoH) does not provide a clear-cut definition of optimal adherence.

However, and according to the guidelines, ideally adherence “(...) rates > 95% (should be obtained) to maximize the benefits of ART” (MoH 2005).

During the adherence-classes held at the CTC optimal adherence was defined as taking the medication regularly, without missing a pill and with exactly 12 hours between the first dosage in the morning and second dosage in the evening. If more than 30 minutes had passed according to the actual pill taking patients were advised to skip the dosage. However, and according to our knowledge, no universal definition of adherence existed at the department. Pharmacist defined non-adherence by patients as not taking their medication regularly and missing more than a full day of pill taking, or having left over pills of more than two days. When we asked interviewees about their adherence rates, women recited precisely on what they had learned in the adherence classes.

During our interviews women showed manifold strategies (12 different strategies in total) in order to ensure adherence to antiretroviral treatment. First, women indicated numerous reasons, which helped them to generally adhere. While some women indicated the education of the importance of optimal adherence received at the CTC as the reasons to be adherent (7 women, 11.5%), others indicated the need to obey to what the doctors say (21 women, 34.4%). However, a connotation of fear resonated within both factors mentioned. One woman justified her being adherent the following:

„(...) I was informed that with this drug it is not allowed to miss even a single day, or fail to follow the hours. Because when you delay or fail then you are causing resistance to those viruses. That is why you need to be careful at any time, because you must swallow at that time and a day should not pass without swallowing“ (Interviewee 24, Section 143).

Another interviewee told us:

“I am afraid since we have been told that failing to take the dosage for only one day the virus then starts to emerge [i.e. multiply]. When you have taken it, it sleeps. It does not die, but it is sleeping“ (Interviewee 34, Section 26).

A total of 17 women (27.9%) indicated that their life depends on regular drug taking. Women also reported their religious faith as a reason to take the medication regularly (8 women, 13.1%). Furthermore, sickness prior to ART commencement (6 women, 9.8%), the fear of recurring sickness (1 woman, 1.6%) and a stable health condition (6 women, 9.8%) since therapy was indicated as a reason for following the treatment plan. One interviewee explained her reason for being adherent the following: “It is because in the past I was very sick. That is why I can not stop taking the medications“ (Interview 8, Section 27). Another woman argued her not forgetting the dose saying: „(...) because I want to live! I know if I

stop or forget to take my medication then someday a problem will happen“ (Interviewee 101, Section 480).

Additionally, being used to taking the medication regularly (8 women, 13.1%) and carrying them wherever they go (8 women, 13.1%), helped in securing general adherence.

Strategies in order to remember regular dosage taking were manifold (10 in total). While many women (31 women, 50.8%) were supported by people, helping to remember to take their dosage on time, many had a watch (12 women, 19.7%), a mobile phone (5 women, 8.2%) or an alarm clock or a radio (7 women, 11.5%) to remember them of their time of pill taking. However, few (2 women, 3.3%) indicated taking them before their daily activity or a certain meal, while again few followed either the prayer of the Muazzin (3 women, 4.9 %) or the sunrise and sunset (2 women, 3.3%) as a substitute to remember and take ART regularly. Again two women (3.3%) remembered their regular dosage taking by writing in a book, while one interviewee (1.6%) mentioned to always take her dosage after her having a meal.

4.2.4 The Perception and Impact of HAART

Many women (13 women, 21.3%) felt thankful for treatment availability, and expressed relief (1 woman, 1.6%) or hope (15 women, 24.6%). As one woman told us:

„As I told you, I would have died because of this problem at any time, while after given treatment [i.e. ARVs] days are moving on. In addition, when you follow the regular treatment schedule you may reach the age God has planned. We thank those who discovered these drugs!“ (Interviewee 10, Section 114).

Interviewees also reported of a dramatic health improvement (38 women, 62.3%) and a positive change in life (13 women, 21.3%), as well as a new independence gained due to a better health condition (3 women, 4.9%). As one woman said: “I thank God they [i.e. ARVs] have helped me. Until now I can walk by myself! I come alone to the hospital. Previously, my mother had to bring me.“ (Interviewee 17, Section 171).

However, four women (6.6%) told us of their fear coming along with the medication and others of rumors about people suddenly dying due to ART (2 women, 3.3%). Furthermore, one woman (1.6%) experienced forced disclosure, while nine women (14.8%) reported of discrimination due to the possession, picking or taking of medication or their sudden health improvement being questioned by others. The fear of involuntary disclosure also led to the need of lying (14 women, 23.0%), as described by one of our interviewees, when asked whether she tells her neighbors that she is going to the CTC to pick up her medication:

„The ones I tell [i.e. of going to the CTC] are my father, my mother and my children. But how will a neighbour help me even if I tell (him/her)? Mostly it is to announce that

(I am) infected which does not help me. I stay with them [i.e. my neighbors] inside [i.e. in the same house] there but I have not revealed even one of my secrets. Today I have left (to come to the CTC), telling them that I am going to have my tooth extracted since the day before yesterday I had a toothache. (...) what will a neighbour help me with, rather than announcing after I have told him/her? He/she will just announce me. Wherever you will stay, you will not be happy. ‘She is already infected with the HI-Virus’ (they will say).” (Interviewee 28, Section 60).

And another interviewee says: „I tell them I just feel to have fever. I am using malaria medications or something else. That is all. I do not disclose so much“ (Interviewee 11, Section 150).

Furthermore, women reported hiding of pill taking (21 women, 34.4%), picking (18 women, 29.5%) or storing them (17 women, 27.9%), in order not to be involuntarily disclosed due to the possession of medication, as described by one interviewee when asked where she stores her medication: “(I store them) in a plastic bag. Then I hide it under the bed because there it is not possible for anybody to see it“ (Interviewee 8, Section 26).

And another women told us:

„(In) our home (...) we are a lot of people. Somebody will get in and will start looking around. ‘What are these bottles here for? Give them to me so that I can store something in them!’ (...) That is why now I use to hide them and if I finish [i.e. the pills] I look for a place and burn it [i.e. the bottle] or I throw it somewhere so that nobody knows“ (Interviewee 34, Section 14).²²

4.3 Results of the M.A. Thesis in Comparison to the Medical Doctoral Thesis

The M.A. thesis describes in detail the numerous experiences by the selected women related to discrimination and their HIV-status. Self-discrimination has only been rarely described by the women interviewed. Overall the influence of the hospital setting was apparent while biomedical terms (such as CD4 Count) were frequently used by the six women portrayed. Several explanatory approaches related to their disease and illness existed interchangeably while God and believing in God played a major role related to their destiny and disease. Furthermore, the normalization of HIV – referred to as “normal” – played a prominent role as a potential coping strategy.

The medical doctoral thesis focuses on rates, patterns and reasons in relation to disclosure of the HIV-seropositive status. All HIV-seropositive women interviewed had partially disclosed their HIV-status while the majority has disclosed to more than one person. In comparison to

²² At the time of data collection the plastic containers with ARVs were highly visibly labeled with the medication name and – depending on the brand – a red ribbon flag, widely known in Tanzania as a symbol for HIV and AIDS.

previous studies women disclosed to more people - almost a quarter however did not inform their husband. The major reason for disclosure was the hope for support. Also antiretroviral therapy was mentioned frequently as a reason, which has not been thematized in previous publications.

HIV-seropositive women in Tanzania are confronted with numerous challenges related to their disclosure due to socio-economic dependency. Interviewed women were deeply dependent on the hospital setting and its staff, and recommendations as well as pressure by the care takers have influenced their decisions related to disclosure. Despite the availability of antiretroviral therapy disclosure of the HIV-seropositive status remains a highly stressful event.

5. Discussion

Prior to access to treatment, reactions to disclosure have been researched within Sub-Saharan Africa, Southeast Asia, the USA and Western Europe, as summarized by reviews conducted by Medley et al. (2004) and the WHO (2003b).

Within the United Republic of Tanzania only few studies have focused particularly on the outcomes of self-disclosure prior to universal access to treatment (Kilewo et al. 2001; Maman et al. 2003). However, these studies have concentrated on reactions to partners only with positive reactions significantly exceeding those of negatives. Since the availability of treatment, again only few studies have been conducted in Tanzania (Greeff et al. 2008; Lugalla et al. 2008; Moyer 2012; Bohle 2013; Bohle et al. 2014), with an emphasis on negative reactions to self-disclosure.

Within this summary we could present unique and detailed information on negative, positive, as well as further reactions experienced by HIV-seropositive women in Tanzania following disclosure. Noticeably, and despite ART, results resembled those of studies conducted prior to ART availability. However, results are of great interest when it comes to women reporting of massive discrimination experienced in particular by non-relatives following self-disclosure and despite treatment availability.

As can be seen from our results and confirmed by the TACAIDS et al. (2008), the expectation raised with the implementation of universal access to treatment, leading to a massive decrease of discrimination within the community has not come true. In the contrary and according to informal interviews with staff from the Deutsche Gesellschaft für Internationale Zusammenarbeit (GIZ) in Dar es Salaam and the BRH hospital staff in October 2013, discrimination due to HIV-infection in Tanzania remains high. Nevertheless, since treatment availability reactions to disclosure experienced by our interviewees differed and were not solely negative as presented by the studies previously conducted by Greeff et al. (2008) and Lugalla et al. (2008).

With the availability of ART a change in disease perception developing from a deadly to a chronic and treatable disease was anticipated by advocates of universal access to treatment. As could be observed by Roura et al. (2009), this development has taken place among HIV-seropositive patients registered at a CTC in Northern Tanzania, with a *normalization* of HIV seem to have occurred. Roura et al. (2009) analyzed numerous reasons leading to the process of *normalization*, with some reasons revealed resembling our results. However, within our

results we could identify further unique reasons leading to a *normalization* of HIV among HIV-seropositive clients at the hospital setting enrolled on ART. Apart from meeting innumerable infected people at the CTC, the high prevalence of HIV among the surrounding population and the high number of families affected, as well as the possibility of treatment might have led to the perception of HIV being a *normal* disease. Furthermore, women were elucidated of different possible modes of infections taught at adherence classes at the CTC, such as sexual intercourse, physical injury or nursing, possibly leading to the assumption of HIV being a *normal* disease, as it could be easily acquired and was seen as a destiny that could affect anybody, as mentioned by our interviewees. Results presented here show an unexpected disease perception, which can be explained the following: first, with the development of coping strategies possibly leading to a reduction of self-stigma among PLWHA. And second, with the influence of hospital staff on shaping opinions, as outlined by Mattes (2011; 2014). The perceptions expressed are promising but at the same time alarming, in regard to prevention of further transmission. The process of normalization in the context of HIV and AIDS and free antiretroviral treatment needs to receive further attention in future research, not only among people infected but also among the overall Tanzanian population.

Despite opponants' doubts, studies certify high adherence rates among PLWHAs enrolled on ART in resource-poor settings. However, reasons and strategies fostering optimal adherence, as well as perceptions and impact of ART onto the lives of infected since treatment availability remain mostly unknown.

Results concerning reasons for adherence to ARVs among patients enrolled on ART in Tanzania have been published by Watt et al. (2009). While most results resembled our findings, further insights into reasons supporting adherence to ART mentioned by our interviewees, such as faith, the medical knowledge of the importance of optimal adherence, as well as fear of (recurring) sickness were presented here. Furthermore unique data on the impact of ART onto the lives of infected within the Tanzanian setting were highlighted. While interviewees reported of improved health conditions, relief and hope in connection with ART, women also had to bear challenges coming along with treatment, such as avoiding involuntary disclosure and discrimination due to medication.

However, the study contains several limitations. First, a relatively small number of patients (n=61, and n=59 respectively) were interviewed, leading to a restriction of generalizations. Second, with exclusively female patients interviewed, gender-specific comparisons between clients could not be drawn, while future studies should possibly include both, men and women. Third, results presented here need to be seen as context-specific and demand

cautious interpretation as the study was solely conducted in a clinically based setting. For possible generalizations of results further extensive ethnographic studies within the environment of infected and within the communities in Tanzania would contribute to a higher understanding.

6. Conclusion

With the implementation of universal access to treatment great hope was raised concerning a change of disease perception, hence leading to a decrease in “(...) denial, stigma and discrimination...” (WHO 2003a, p. 6) as outlined above. As can be seen from the results, these hopes were only fulfilled to some extent. With the implementation of ART an expressed *normalization* of HIV among our patients visiting the hospital could be observed. However, it needs to be presumed that several factors – such as the high prevalence rate, a high number of people directly or indirectly affected, mandatory counseling prior to ART commencement – and apart from the availability of ART, lead to the expressed process of normalization of HIV. As these results are context-specific, this development can be interpreted as a pleasant development in regard to a decrease in self-stigmatization and coping with the disease among people infected with HIV. However, at the same time this process is also highly alarming with regard to prevention of further transmission. It needs to be investigated in future studies, whether the expressed perception actually translates into lived actions and if so to which extent. While this development asks for close observation in the future, further research within the communities is urgently needed.

Nevertheless, results can lead to the cautious assumption that despite treatment availability, a reconceptualization of HIV among the general community does not seem to have occurred, with levels of discrimination in the context of HIV and AIDS among the overall community remaining high in Tanzania, as confirmed by informal interviews in Tanzania in 2013.

With positive outcomes coming along with ART, such as a stabilization of health, hope and relief, ART also bears great challenges imposed upon people infected and their respective environment, such as discrimination due to pill taking and the fear of involuntary disclosure.

Hence, the social support for people infected and their environment is more than ever of urgent need and greatly missing. Knowledge of the social impact of ART – such as the process and outcome of disclosure, the perception of HIV and AIDS and the effects of ART – is of crucial importance for future public health interventions in regard to the planning of prevention and support programs for people enrolled on ARVs.

Since the implementation of (universal) access to treatment, the social impact of ART has been significantly neglected, while further multi-methodological research, providing detailed and culturally adapted results in the future and a debate on the social impact of the implementation of access to free ART onto the lives of people infected with HIV is urgently needed.

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8. Link to the Publication

Bohle LF, Dilger H, Groß U (2014) HIV-serostatus disclosure in the context of free antiretroviral therapy and socioeconomic dependency: Experiences among women living with HIV in Tanzania. *Afr J of AIDS Res* 13(3), 215-227, DOI: 10.2989/16085906.2014.952646

Link: <http://dx.doi.org/10.2989/16085906.2014.952646>

Acknowledgement

I would like to deeply thank Prof. Dr. Hansjörg Dilger from Freie Universität Berlin and Prof. Dr. Uwe Groß from Göttingen University, who accepted me as their doctoral candidate and who greatly supported, inspired and motivated me throughout my “doctoral journey”. My special thanks goes to Prof. Dilger for accepting me as his (medical) doctoral student and for sharing his great knowledge, providing endless support, for his reliability and helpful critical thoughts in the field of medical anthropology and beyond.

I am deeply indebted to every single woman of the CTC, who agreed to be interviewed and who were the core of this study.

For the financial realization of the research project I would like to thank the *Gö4med* scholarship of the Medical Faculty of Goettingen University and the *Deutscher Akademischer Austauschdienst* (DAAD).

My thanks goes to the Ethical Committee of the Medical Faculty of Goettingen University and the *National Institute for Medical Research* (NIMR) for ethical approval, as well as the *Commission for Science and Technology* (COSTECH) for granting research permission.

I want to express my deep gratitude to the whole team of the *Deutsche Gesellschaft für Technische Zusammenarbeit* (GTZ, now *German International Cooperation* (GIZ)) in Dar es Salaam, in particular the *AIDS Office* and *Tanzanian-German Programme to Support Health* (TGPSH) for their generous technical support by granting me the needed facilities in Tanga city. Without their help, the realization of the research study would not have been possible. Especially I would like to thank Dr. Bergis Schmidt-Ehry, Dr. Angelika Schrettenbrunner, Cornelia Becker, Dr. Balthazar Ngoli, Dr. Yunus Koshuma and Dr. Rainer Külker.

I am thankful to Dr. Pascal Kanyinyi, at the time Regional Medical Officer of Tanga Region and local partner of the study. Thank you to Mr. Selemani Msangi from National AIDS Control Programme (NACP) and Simon Collery, who always lended a helping hand and who I tortured with questions on data concerning HIV and AIDS in Tanzania – and still do. My thanks goes to Dr. Ferdinand Mtatifikolo, at the time director of Bombo Regional Hospital and Dr. Margret Mhando for allowing me to conduct the study at the hospital site. I am thankful to the whole staff of the CTC of Bombo Regional Hospital – in particular the medical doctors who helped in the recruitment of interviewees, as well as the clerk staff, the pharmacists, the nurses and the VCTC team.

Furthermore I would like to thank Dr. Peter Mangesho for his help in finding a research assistant. I am deeply thankful to Lilian Mbwambo and Grace Mwakipesile Preuss, my interviewers, for their fantastic work done during the study, as well as Alex Mkwizu and

Beatrice Siteyian for translation of the interviews. Besides I want to thank Dr. Peter Memiah and Daniel Ole Mtalami for giving me insight into the work of *AIDSRelief* and helping me with further access to literature, as well as Dominik Mattes for his help.

Furthermore, I would like to thank Dr. Peter Hellmold, Dr. Joseph Mberesero and Anna Bezold for sharing their clinical knowledge with me at Bombo Regional Hospital between 2002 and 2008 and inspiring me.

I would like to thank Dr. Alexandra Müller and Katharina Dittmer, who helped in guaranteeing inter-coder reliability for the analysis of interviews conducted and Frank Albert for further translation. For statistical support I want to thank Dr. Jakob Siemerikus and Dr. Andreas Cordes. Lisa Mackenrodt I want to thank for her professional help in the interpretation of Swahili terms. To Dr. Julia Wangari Muchunu, Dr. Joseph Mberesero, Luiza Zena Robi, Lilian Mbwambo, and Grace Mwakipesile Preuss – thank you for sharing your knowledge regarding Tanzania and Tanga. For a thorough proofreading of this thesis I want to thank Heather Midgordon and Renate Laut from Göttingen University.

I would like to thank the Freundes- and Förderkreis of the Medical School of Goettingen University, which granted me a scholarship for a clinical elective at the Groote Schuur Hospital in Cape Town, South Africa in 2006. The experiences gained highly influenced me in the development of the questions investigated throughout this research project.

Last but not least my special thanks goes explicitly to everyone not listed above but who supported me in person and in the research project in general.