Leah Franziska Bohle

Stigmatization, Discrimination and Illness

Experiences among HIV-Seropositive Women in Tanga, Tanzania

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Table of Content

Figures

Diagrams

Tables

Abbreviations

AIDS	Autoimmune Deficiency Syndrome
AMO	Assistant Medical Officer
ASAP	AIDS Strategy & Action Plan
ART	Antiretroviral Therapy
ARVs	Antiretrovirals
BRH	Bombo Regional Hospital
AVERT	Averting HIV and AIDS
CD4	Cluster of Differentiation 4
CIA	Central Intelligence Agency
CTC	Care and Treatment Center
DAAD	Deutscher Akademischer Austauschdienst
GTZ	Deutsche Gesellschaft für Technische Zusammenarbeit
GIZ	Deutsche Gesellschaft für Internationale Zusammenarbeit
HIV	Human Immunodeficiency Virus
HAART	Highly Active Antiretroviral Therapy
ICW	The International Community of Women Living with HIV/AIDS
IWHC	International Women's Health Coalition
MEASURE DHS	MEASURE Demographic and Health Service
MoEVT	Ministry of Educational and Vocational Training
MoH	Ministry of Health

MoHSW	Ministry of Health and Social Welfare
NACP	National AIDS Control Programme
NGO	Non-Governmental Organization
PEPFAR	The United States President's Emergency Plan for AIDS Relief
PLWHA	People Living with HIV/AIDS
PLHIV	People Living with HIV
PMTCT	Prevention of Mother to Child Transmission
PO	Participant Observation
TACAIDS	Tanzania Commission for AIDS
TGPSH	Tanzanian-German Programme to Support Health
TZS	Tanzanian Schillings
UN	United Nations
UNAIDS RST ESA	Joint United Nations Programme on HIV/AIDS – Regional Support Team for Eastern and Southern Africa
UNGASS	United Nations General Assembly Special Session
UNICEF	United Nations International Children's Emergency Fund
UNDP	United Nations Development Programme
US$	United States Dollar
U.S.A.	United States of America
USAID	United States Agency International Development
VCT	Voluntary Counseling and Testing
VCTC	Voluntary Counseling and Testing Center
WHO	World Health Organization

Introduction

Since the first AIDS case was officially reported in the United Republic of Tanzania[1] in 1983 the disease has developed into a pandemic[2] in sub-Saharan Africa, with approximately 22.5 million people infected and 1.3 million HIV-related deaths in 2009 (UNAIDS 2010b:6).[3]

From a biomedical viewpoint the Human Immunodeficiency Virus (HIV) causes the deadly Autoimmune Deficiency Syndrome (AIDS), attacking the immune system until its final breakdown and death of the infected person. Nearly three decades later, only life extending medications are available and a cure has yet to be found.

Besides its impact on the lives of infected individuals and the surrounding society, the disease has a tremendous impact on the political and economic status of sub-Saharan countries.

During numerous visits to Tanzania between 2002 and 2008 (at the time as an anthropological and medical student), I became most aware of HIV[4] as a devastating disease. I was not only faced with hospitalized patients suffering from the disease – who often tried to hide their seropositive status[5] – but was also confronted with its impact on daily life, as friends, having disclosed their HIV-seropositive[6] status suddenly fell sick and passed away, leaving behind their beloved families and children.

During preparations for the research project in 2007 Tanzanian president Jakaya Kikwete launched an HIV-testing campaign, passing through every large city in the country offering HIV-tests free of charge, while antiretroviral therapy (ART) was available in greater hospitals for free.

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[1] Throughout the book the term *the United Republic of Tanzania* will be replaced by the term *Tanzania* for better readability.

[2] Within this book it will be referred to the term *pandemic* as used by Paul Farmer and Jim Yong Kim in the book *Women, Poverty and AIDS* (1996) and defined by the World Health Organization (WHO) as "…a worldwide epidemic of a disease" (2011:n.p.), expressing that the virus has spread globally, not being restricted to geographic boundaries, as with referring to the term *epidemic*.

[3] For further information please see TACAIDS (2009:1).

[4] When talking about HIV it is referred to the infection by the virus and therefore the disease in a biomedical sense and its illness experiences caused by the Human Immunodeficiency Virus rather than the virus itself.

[5] During a medical clerkship in 2007 at the *Department of Gynecology and Obstetrics* of the BRH I could observe that some women giving birth at the ward had either scratched away the sign made by the doctors signifying their HIV-seropositivity in their hospital identity card (which they must show before giving birth), or they even had two hospital cards, one claiming that they had yet to be tested for HIV and the other declaring their HIV-seropositive status.

[6] Within this book the term *HIV-positive* will be used equivalent to the term *HIV-seropositive* or *being positive*.

The results presented here are part of a larger research study focusing on verbal disclosure among HIV-seropositive[7] women at the Bombo Regional Hospital (BRH) in Tanga, Tanzania.

During the quantitative and qualitative research study phase every woman interviewed unexpectedly reported either feared or experienced discrimination by a third party in the context of disclosure,[8] although the form of discrimination was manifold. Additionally women reported self-stigmatizing attitudes in the context of their HIV infection.

Within this book I want to shed light on the experience of *illness* and *disease* accompanied by *discrimination* and *(self-)stigmatization*, particularly in the context of HIV and AIDS from a medical anthropological and public health viewpoint. The results of six outstanding interviews conducted will be presented in order to underline the experiences of HIV-seropositive women in Tanzania, illustrating the tremendous impact that accompanies the diagnosis of having a *disease* and *being positive* on the lives of HIV-positive women.

As this work is embedded in the sub-discipline of medical anthropology, the reader will be briefly elucidated of the focus and historical development of this discipline. Its important role and achievements in trying to understand illness and disease will be indicated, further introducing its numerous disciplines and methodologies as well as its outstanding role within HIV and AIDS research.

To avoid terminological unclarity, explanations and possible definitions of the terms in use will be provided.

A thorough examination of the terms *illness* and *disease* in the literature – especially from a social anthropological viewpoint – will be presented, with primary reference to Arthur Kleinman.

Furthermore information on the topic of *(self-)stigmatization* and *discrimination* experienced alongside *illness* will be provided. Hereby the most important literature, referring to Erving Goffman (1963) and others, will be discussed and suitable explanations and possible definitions of the terms in use will be given, as well as their role in the context of HIV and AIDS clarified.

In order to better understand the impact of HIV and the enormous consequences brought up with a positive diagnosis, briefly more information on HIV and AIDS from a biomedical standpoint[9] will be given, as well as the international position regarding the pandemic alluded.

In order to understand the social and cultural background of the study and the impact of the disease in Tanzania, information needs to be provided concerning

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[7] By using the term of *being HIV-(sero)positive,* being *positive* or *living positive(ly)* it is referred to the diagnosis of being infected by the HI-Virus.

[8] For further information please see Hanne Mogensen's chapter on disclosure titled *New hopes and new dilemmas: Disclosure and recognition in the time of antiretroviral treatment* in Dilger (2010).

[9] From here onwards and when using the term *biomedical medicine*, it will be referred to medicine as practiced in western European countries.

HIV in Tanzania and the governmental response to the pandemic, as well as its response to discrimination and stigmatization in the context of HIV and AIDS.

Before presenting results of the study conducted, further information will be given concerning the focus of the research study, its setting, the research procedures, the study participants, and the protection provided to enrolled participants. Furthermore the methodology used will be explained in detail, including data collection, the processing of data material, as well as the final data analysis. This will be followed by a presentation of the interview results.

Finally the results are thoroughly interpreted and discussed in light of published literature and personal experiences. Last but not least the book will conclude with a summary of results and a projection of future developments.

1. Medical Anthropology

The chapter provides an overview of the sub-discipline of medical anthropology, in which this work is embedded. First the focus of the discipline will be explained, before briefly presenting its historical development, as well as recent developments within this field. Additionally insight into the methodologies used and the role of the sub-discipline within HIV and AIDS research will be given.

1.1 Medical anthropology – a discipline on the move

Anthropology in general – as a part of social science – is a discipline engaged in studying human beings and "…the features of both their society and their culture" (Helman 1990:2) while "[a]nthropologists seek to understand similarities and differences in behavior and biology across cultures and populations…" (Allen and Wiley 2009:2).

Thus, the discipline investigates multiple facets of culture in a society such as language, customs, religion, medical and belief systems. Medical anthropology explicitly "…concerns itself with the many factors that contribute to disease or illness and with the ways that various human populations [experience and] respond to disease or illness" (Baer 1997:3).

Hereby "…culture should be understood as neither static nor totalizing" (Lock and Nguyen 2010:7) especially in our globalized and transcending world wherein one can move through cultural settings within hours or even minutes. However, it should rather be seen as

> *"…one possible system of reference through which people engage in historical processes and through which they make choices and decisions in relation to other systems of reference and identification (...) that provide knowledge about the way human beings are situated in society and the world order at large"* (Dilger 2010:7).

Medical anthropology is known as a comparatively new and dynamic sub-discipline of anthropology and one of the fastest growing. It derives from physical anthropology, ethnomedicine, cultural anthropology, and public health (Anderson and Foster 1978:4-8). The word composition already illustrates the connection of anthropology as a discipline and medicine in general as the subject area.

Cecil Helman summarizes the discipline of medical anthropology as follows:

> *"Medical anthropology is about how people in different cultures and social groups explain the causes of ill-health, the types of treatment they believe in, and to whom they turn if they do become ill. It is also the study of how these beliefs and practices relate to biological and psychological changes in the human organism, in both health and disease"* (1990:1).

Medical anthropology as a discipline has been developing in numerous countries.[10] In the United States (U.S.A.), the development dates to the 1920s, specifically dealing with traditional medicine, shamanism, divine healers, and witchcraft,[11] while William Rivers, a physician and anthropologist, was probably among the first to discuss "…health-related issues cross-culturally…" (Baer 1997:15). Since then, numerous researchers have focused on related topics dealing with illness, disease, and health in a culturally comparative context, further shaping the sub-discipline.[12] While medical anthropology was rising in the U.S.A.,[13] Great Britain was setting milestones with the 1972 foundation of the *British Medical Anthropology Society* (Baer 1997:18).

In Germany the combination of anthropology and medicine – and a precursor of what is known today as public health - was established by Rudolf Virchow, a well-known and influential physician and scientist at Berlin Charité, and Adolf Bastian, a physician and professor for cultural anthropology in the late 19th century (Baer 1997:15; Saillant and Genest 2007:143). During the Nazi regime the academic progress in this field declined and recommenced in the postwar period in the 1970s (Baer 1997:18).

German universities institutionalized medical anthropology[14] beginning in the 1980s (Saillant and Genest 2007:146). In 1997 the *AG Medical Anthropology* was founded as part of the *Deutsche Gesellschaft für Völkerkunde*, offering various workshops and training in medical anthropology (AG Medical Anthropology 2011).

While medical anthropology is a common and well-established discipline in the U.S.A. and England, the discipline is slowly gaining ground in Germany[15] – although as seen from the historical outline, medical anthropology is making steady progress.

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[10] For further reading on the development of medical anthropology please see Anderson and Foster (1978). Furthermore the book *Medical anthropology: Regional perspectives and shared concerns* written by Genest and Saillant (2007) can be recommended, as it provides a detailed overview of the different regional developments throughout several chapters dedicated to specific countries.

[11] One of the most influencing works at that time was probably *Witchcraft, oracles and magic among the Azande* by Evans-Pritchard (1937).

[12] Fur further information please see Arthur Kleinman's book *Patients and healers in the context of culture* (1981).

[13] For further information please visit the website of the *American Anthropological Association* (AAA) (American Anthropological Association 2011), as well as the website of the *Society for Medical Anthropology* (SMA), a branch of the AAA, founded in 1970 and dedicated to medical anthropology (Society for Medical Anthropology 2009) at http://www.medanthro.net/ [09.05.2013].

[14] In the German language a pluralism of terms for the English term of medical anthropology exists. *Ethnomedizin* as well as *Medizinethnologie* are individually used while according to Lux no accurate discriminatory power exists so far (2003:14).

[15] Medical anthropology as a single course of study is not offered at German universities until now.

Numerous sub-disciplines have evolved within medical anthropology such as transcultural psychiatry,[16] clinically applied medical anthropology - focusing on preventive and applied aspects in clinical settings -, anthropology in international and public health, as well as critical medical anthropology – concentrating on inequality among societies within health and disease. Paul Farmer as well as Nancy Scheper-Hughes, among others, are famous representatives in these fields (Helman 2008:xvii).

Although multiple core areas within medical anthropology have emerged, no clear boundary exists due to overlapping disciplines. Thus the sub-discipline does not fragment but rather enriches and enhances anthropology, generating "…conceptual advances benefiting the discipline as a whole" (Sargent and Johnson 1996:xx).

Kleinman advocates for medical anthropology as a discipline. He criticizes biomedicine[17], as, and although rational and clear, it requires universal definitions of disease, rather than helping to improve health care (Kleinman 1995:17). To him the overall aim of medical anthropology is to "…propose alternative ways of responding to human problems" (1995:17).

A fortiori medical anthropology as a discipline is needed in a globalized world in order to understand disease, illness perceptions and treatments within a society, as well as to design and support individual effective strategies to combat diseases in the future.

It is indisputable that

> *"... medical anthropology emerges in an increasingly important role, drawing on biological and social sciences, as well as clinical medical practice, to improve health status and health services worldwide"* (Sargent and Johnson 1996:xii).

The anthropological methodology used is qualitative, as well as quantitative. This allows description of illness, disease, health, and treatment in a certain cultural context (Trostle and Sommerfeld 1996:254). Anthropologists consider ethnographic fieldwork as a suitable technique for understanding and describing the *complexities of culture,* since it involves delving into a society and observing and participating in the life of its members, known as *participant observation* (Allen and Wiley 2009:4; Helman 1990:6). It provides an *emic* view: seeing whatever is observed through the eyes of the society, and an *etic* view: being able to retain objectively what one has seen and to *translate* the information into the perspectives of a social scientist (Allen and Wiley 2009:4).

The research results presented within this book can be embedded in the field of international and clinically applied medical anthropology, since it occurred in a

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[16] For further information please see Charles C. Hughes in Sargent and Johnson (1996), titled *Ethnopsychiatry* or Anderson and Foster (1978).

[17] The term biomedicine in use within this book implies medical theoretical concepts and praxis in western industrialized countries.

hospital setting in Tanzania and concentrated on disease and illness while using established anthropological methods coupled with quantitative methods.[18]

1.2 Medical anthropology in the context of HIV and AIDS

The tremendous spread of the HI-Virus since its worldwide first reported case in the 1980s and its development into a pandemic has lead to ever increasing international attention. Medical anthropological research tends to focus on a spectrum of certain diseases or even a single disease in a certain cultural setting, such as HIV and AIDS in sub-Saharan Africa.

Especially in high-prevalence countries the disease has an enormous impact on the social, cultural, political, and economic status, including the health care systems and overall reproductive issues (Trostle and Sommerfeld 1996:261). The rampant spread of the disease in certain countries and its accompanying consequences raises questions that cannot be explained by biomedicine alone.

Paul Farmer is among the most important medically and anthropologically trained researchers in the field of HIV and AIDS worldwide, practicing a critical medical anthropological framework. In Europe several research groups exist and deal with the disease in varying regional foci, examining topics such as the impact of HIV, behavior towards HIV and AIDS or the scale-up of treatment availability of HIV within a cultural context.[19]

The respected opinion of leading international organizations indicates that the spread of HIV can be mainly explained by the most common mode of infection through sexual intercourse and the behavior of high-risk groups. But to better understand the spread of the disease and millions of people infected and dying, we must look to the faces behind the numbers.

Today medical anthropologists are in great demand, as the discipline overcomes reductionism and contributes to better identify the *multiple* factors contributing to the spread of the disease within a society. The aim is to overcome "…selection biases inherent in such sensitive research within stigmatized or marginalized populations" (Trostle and Sommerfeld 1996:261) and to "…recognize the validity of multiple perspectives and to mediate interaction between the various specialists…" (Sargent and Johnson 1996:xviii).

While biomedical facts concerning the disease are widely known, the individual and collective behavior is equally important concerning the disease and the surrounding deaths,

> *"…shaped by socio-moral perceptions and practices that relate people's way of dealing with the disease to broader questions of social and cultural continuity and belonging"* (Dilger 2010:10).

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[18] Detailed information are provided in Chapter 6.

[19] See Dilger (1999; 2005) and Lux (2003).

Ethnographic research – giving a deep insight into societal perception – therefore is of a special importance, contributing to a more profound understanding of this very complex disease.

Finally, according to Kleinman, this work is functioning in an interdisciplinary margin, since "[m]edical anthropology is at the margin of medicine; it is also at the margin of anthropology" (1995:1) whereas "(a)nthropology is (…) in a truly crucial margin between the humanities and social sciences" (1995:2). In addition the study of HIV within a cultural setting can be seen as a topic at the margins of biomedicine itself.

2. Illness and Disease – Inequal Substitutes

Having defined the discipline of medical anthropology referred to in the previous chapter, the terms *illness* and *disease* will be clarified, terms of utmost importance to medical anthropology and the upcoming chapters alike.

The English terms illness and disease lack a discriminatory power in the habitual language use and are closely linked, both referring to the diagnosis of a bodily *abnormality* given, or used in order to paraphrase *the experiences* of being sick.

Within the medical anthropological discourse it is differentiated between the two terminological categories of illness and disease - a concept first introduced by Eisenberg (1977) and emphasized by Kleinman (1988).

The following chapters will be affiliated with the definitions given by Kleinman, for whom *illness* refers to the lived experience of the person being sick and suffering, as well as on how the environment "…perceive[s], live[s] with, and respond[s] to symptoms and disability" (1988:3).

According to Kleinman "[i]llness problems are the principal difficulties that symptoms and disability create in our lives" (1988:4). However, *illness* reaches beyond the affected person and is "…a deviant status, as without appropriate control mechanisms over patient behavior and motivation there (…) [is] a potential risk to social stability" (Armstrong 2000:27).

Coping mechanisms are observable in response *to* illness as multiple challenges in daily life arise, while illness experiences assume the role of being *the* trigger impulse to decide when to seek help and start treatment.

In general coping can be defined as "…constantly changing cognitive and behavioral efforts to manage specific external and/or internal demand" and "…as a process [which generally] applies to all stressful encounters" (Folkman and Lazarus 1984:143).

Folkman and Lazarus differentiate

> *"…between coping that is directed at managing or altering the problem causing the distress and coping that is directed at regulating emotional response[s] to the problem. (…) refer[ing] to the former as problem-focused coping and the letter as emotion-focused coping"* (Folkman and Lazarus 1984:150; emphasis in original).

According to a definition by the Pschyrembel coping in the context of illness, which may be regarded as a stressful encounter, can be seen as coming to terms with one's illness, while successful coping has a high impact on ethiopathology (Hildebrandt, Dornblüth and Pschyrembel 1997:301), such as psychological well-being.[20]

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[20] For further reading on coping mechanisms in the context of HIV and AIDS in Tanzania please see Makoea et al. (2008).

The individual illness experience is undoubtedly shaped and transformed by innumerable factors such as culture, society, politics, and geography and "…is inextricably intertwined with the self and others across time" (McElroy and Jezewski 2000), being of a dynamic character. Charmaz points out that "[w]hether, when, and how people might acknowledge and act upon illness is embedded in culture and context" (2000:277). To this Kleinman comments that

> *"[l]ocal cultural orientations (…) organize our conventional common sense about how to understand and treat illness; thus we can say of illness experience that it is always culturally shaped"* (1988:5),

making illness a field of interest for medical anthropologists.

Moreover "[i]llness acts as a social signifier; it is the subject of discourses which continually call into question the environment in the broadest sense of the word" (Augé and Herzlich 1995:2), acting as a "…violation of the general order" (Augé and Herzlich 1995:7). Therefore illness assumes a threatening character not only for the individual affected but for society in general. Arthur Kleinman and Don Seeman have aptly explained the power of illness. To them

> *"[t]he experience of illness is not [solely] bounded by the bodies or consciousness of those who are ill. It reaches out to encompass a household, a family, or a social network"* (Kleinman and Seeman 2000:231; emphasis removed, L.B.).

For social scientists the concentration on personal illness experiences is therefore crucial.

On the contrary *disease* applies to deviation from the biomedical *state of normality*, whereas biomedicine defines "…health and illness largely in terms of biologically based diseases" (Armstrong 2000:27), translating the patient's[21] complaints into *technical terms* of a particular healing system.

But when is a *disease* called a *disease* and when is somebody *sick* or *healthy*? Before referring to the terms of *disease* and *illness* – especially in the context of discrimination and stigmatization – it is crucial to first discuss the terms of *being normal* and *abnormal*, as they play a central categorizing role in this debate.[22]

According to Jürgen Link different forms of normality, dependent on the context, are integrated into a standard set of benchmark normalities. Behavior is questioned according to this set of standards and adjusted accordingly (Link 2009:20). The set of standards is gathered through repetitive and common experiences in a society (Link 2009:35-36), although interpretation of normality

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[21] When referring to a *patient* it is referred to a person having received a diagnosis by a practitioner, whereas when referring to *the sick* it is referred to a person suffering from illness.

[22] For further information on (ab)normality in the context of disease and illness see Canguilhem (1974).

thus depends on factors including culture, history, and social affiliation and is of a dynamic character.[23]

The idea of normalcy automatically infers inclusion and exclusion and serves as a security standard within a group (Link 2009:20, 39), enabling social cohesion by eliminating outliers.

In this case, the majority embodies the *normal state,* emanating assurance, whereas positioning at the border of this standards set may lead to *denormalization,* which in turn can cause confinement and fear (Link 2009:44).[24]

Physiological processes reoccur over millennia and work to ensure survival. These processes supporting life are reproduced and set a universal standard of normalities, while the *normativity of life* cannot be equated to or confounded with *social normativity* (Link 2009:112-114).[25] Hence the standard set of normalities concerning *disease* is rather *static* and helps us to judge whether something can be defined as a disease or not. These definitions are again according to this standard set of normalities concerning the social life, defining whether a person belongs to the majority group of *the healthy* or to the margin of *the sick*. Standard sets of normality concerning the *social life* are rather *dynamic* while the majority and the minority follow a statistical Gaussian distribution (Link 2009:39).

Especially in comparative studies of illness and medical knowledge the assumption that the own medical knowledge reflects the natural order needs to be questioned and discussed. As Byron Good writes "[o]ur conviction about the truth claims of medical science rest uneasily with our recognition of our own historicity…" (1994:3). Different knowledge claims of medical issues therefore need to be considered and addressed within the discipline of medical anthropology, finally leading to a discussion within cultural relativism and philosophy.

Scholars subscribing to biomedicine[26], defining diseases and giving diagnoses, are often highly criticized by medical anthropologists. Obviously biomedicine is a highly influential discipline that deals with medical issues. Successful in treating diseases, "…it is claimed that biomedicine, because it is grounded in science, has a special technical status based on objectivity and standardization, *independent* of

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[23] On the contrary Goldstein (1934), and according to Link, is questioning the development and existence of general normalities but rather sees them as individually interpreted and categorized (Link 2009:110-115). This method however makes a debate on normality needless. I would rather argue that certain general sets of normality exist, as well as individual categories due to experiences.

[24] The level of threat here surely varies. While some people seek to belong to a minority, possibly being at the margin of a minority, in most societies being at the margin due to sickness is not desirable. And again, being at the margin at one group could lead to being part of a majority society in another cultural and social setting.

[25] For further information on this debate please see Canguilhem (1974), Foucault (1976) and Goldstein (1934).

[26] The use of the term of *biomedicine* is in reference to western medicine as well as to the German word *Schulmedizin*, in contrast to *alternative medicine* such as acupuncture or homeopathy.

society and culture" (Lock and Nguyen 2010:53; emphasis added, L.B.). Thus biomedically-trained professionals all over the world tend to neglect other approaches to illness and disease as health problems, while biomedicine itself seeks for universality. Firstly, medical anthropologists, such as Kleinman (1995), criticize biomedicine for its ethnocentristic position, claiming *to listen* more carefully to the stories told by the sick in order to better *understand* illness and disease. Although Kleinman (1995:31-32) disapproves of the reductionary influence of biomedicine on medical practitioners, biomedicine's position in western setting nevertheless warrants defending as patients often expect concrete diagnoses from their practitioners.

Secondly, medical anthropologists animadvert the implementation: the biomedical viewpoint of health problems aims to simply *reduce experiences*, discover a causality, subscribe to a pathology and arrive at diagnosis, ideally leading to a treatment (Augé and Herzlich 1995:15). By doing so *illness experiences are neglected* and feelings reduced, leading to a dehumanizing practice in dealing with suffering individuals (Kleinman 1995:31) – the actual sufferer is ignored.

But in order to understand the perceptions of illness and disease and to provide relief through treatment, the beliefs and the experiences of the sick *and* society must be taken into account – especially in an unknown cultural setting (McElroy and Jezewski 2000:206).

Kleinman stresses the importance of studies dealing with the experience of illness and disease (1995:9), hence being able to provide important information on the "individual level" of illness experiences and perceptions, the "interactional level" of health care and the "institutional level" of health policy (Charmaz 2000:277).

Especially *focused ethnography* conducted by medical anthropologists represents an effective tool in order to conduct social and health-related studies of particular illnesses (McElroy and Jezewski 2000:205), which

> *"…help (…) achieve a better understanding of the nature of our collective reasoning, of our social thinking on illness. They then lead us to reconsider the role of medicine, its institution and its knowledge, in the way the West conceptualizes and assumes responsibility for illness, health and bodily phenomena" (*Augé and Herzlich 1995:13).

In sum we can infer that illness experiences, influenced by numerous factors, can be seen as the interpretation and expression of a *bodily abnormality*, while the status of *abnormality* refers to the margin of a set of majority standards. People affected by illness hence try to cope with the illness and disease, attempting to reduce negative influences onto their lives and seek to ensure relief or even well-being.

In order to better understand and support the person suffering from illness, careful observation and listening to the patient's expression of illness is crucial. The reductionist character of *disease* and the claim of a universal validity of biomedicine need to be questioned. Kleinman even demands "[w]hat we need now is a much deeper phenomenology of the forms of social suffering. (...) a phenomenology of a wide spectrum of experiences but not just for clear cut diseases“ (Kleinman 2011:n.p.).

2. 1 Chronic illness – leading to lives of inconsistency

Within this book we deal with chronic illness as examined by Kleinman in his book titled *Writing at the Margin* (1995). When talking about chronic illness one refers to ongoing illness, whereas illness experiences can either be chronic, episodic or a combination of both. Although the disease cannot be cured, symptoms experienced can be made more tolerable. Furthermore functional individual coping mechanisms and a supportive environment can lessen suffering.

A common behavior among the chronically ill is to exploit all possible options of treatment – these may be homeopathy or herbal medicine, aimed at bringing relief and strengthening the body against the chronic disease in an apparently hopeless situation. On the one hand, a biomedical perspective tells us that practitioners offering alternative treatments profit from the incurability of chronic disease. On the other hand, these practitioners often provide support, such as hope, to the individual suffering from illness (Kleinman 1988:46).

The constant illness involuntarily becomes part of the life of the sick person and its influence on the patient routines is further enhanced by its duration. Charmaz writes "[c]hronic illness poses more social, interactional, and existential problems than acute illness *as it lasts*" (Charmaz 2000:277; emphasis added, L.B.). The character of the illness as an unstable condition and the constant possibility of change or worsening symptoms has tremendous impact on patient lives. The unpredictable nature of chronic illness may worry and wear the affected person. Due to this condition "[t]he chronically ill live at the margins" (Kleinman 1988:44), while in the long run chronic illness can cause loss of confidence and hopelessness (Kleinman 1988:44-45).

Hence, chronic illness might have long-term negative effects on a person's relationship, career, and daily activities (Kleinman 1988:46), potentially compromising the quality of life and psychological well-being. Additionally patients suffering from chronic illness possibly spend much time in health facilities, and are often bound to a tight treatment regiment that controls their life in many ways, from a special diet to the strict timing of pill taking, wherein disease treatment dictates the daily life rhythm, not vice versa.

Apart from the physical loss of time due to illness, most patients are constantly interpreting and judging their symptoms, often trying to downplay their significance, an act that Kleinman (2011) terms *self denial*, whereas deception makes the illness tolerable (Kleinman 1988).

He points out,

> *"…the meanings of chronic illness are created by the sick person and his or her circle to make over a wild, disordered natural occurrence into a more or less domesticated, mythologized, ritually controlled, therefore cultural experience"* (1988:48; emphasis removed, L.B.).

On the other hand the chronically ill also tend to *normalize* their symptoms, trying to find alternative ways of making sense of their bodily sensations (Charmaz 2000:282). The definition of *normalcy* is culturally and individually determined, while the term *abnormal* describes "…the idea of [minimal] deviation by degree from a norm, and the idea of a perfect state" (Lock and Nguyen 2010:46).[27]

Normalcy can be seen as a coping strategy serving not only the purpose of adapting to the new situation, but proceeding with daily life *as normal*, hereby staying involved in society (Charmaz 2000:283). The construction of normalcy can be regarded as an attempt "…to close the gap between 'is' and 'ought', and so has a moral quality build into it" (Lock and Nguyen 2010:46). Staying *normal* hereby implies "… finding ways to minimize the impact of illness, disability, and regimen on daily life, including their visibility" (Charmaz 2000:283), hence avoiding stigmatization and discrimination such as exclusion from daily life due to difference.

The price for forced construction and the living of a *normal life* is often high, especially when compared to the benefits of giving hope for the actual lives lived. To request help due to illness experience while at the same time longing to belong to the *normal* may understandably be complicated.

In conclusion, the incurability of chronic illness (such as HIV and AIDS), alongside its constancy and unpredictable progression, implicates significant interference in patients' lives. Chronic illness therefore demands that patients adopt coping strategies to imitate the life of a *normal.*

Again, ethnographic methods are of great importance as "…we must study what ill people think, feel, and do in their natural settings" (Charmaz 2000:277) in order to better understand experiences lived and the impact of these illnesses on daily life.

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[27] For further information on the debate of *normality, normativity and nature* please see Jürgen Link (2009:112).

3. Stigmatization and Discrimination – An Explanatory Approach

The terms *stigmatization* and *discrimination* lack common and clear differentiation and are often used interchangeable in the literature. This leads to a degree of academic uncertainty and even confusion (Geiselhart 2009:38). Within the following chapter, I will explore and define the two terms and differentiate them accordingly. In doing so, I will rely on theories found in Erving Goffman's book titled *Stigma: Notes on the management of spoiled identities* (1963), in which he provides the most profound modern theoretical discussion of stigma, as well as Klaus Geiselhart's (2009) critical examination of the terms in use.

To begin, the terms have different etymological roots. *Stigma* derives from ancient Greek, meaning *mark* or *brand* (Partridge 1977:4176). Since then the term has undergone changes in meaning, no longer referring solely to a bodily mark, but also implying the ascription to or the bearing of an attribute that differentiates and distinguishes a person from others. The attribute can be visible or non-visible, of positive, neutral, or negative quality and generally people can bear more than one stigma. To actually *stigmatize* refers to the action of assigning a stigma to an individual. Though, at what point does any one attribute become a stigma?

When Goffman (1979) uses the term stigma, he refers to an attribute deviating from the norm, with the capacity to differentiate a person. According to him, a normative set of expectations is shared by every society, under which people are judged and categorized. Generally the attribute carries negative connotations, possibly lowering the self-perception of the affected person (1979:157).

Goffman faced criticism from several authors[28] for his narrow definition of stigma, as he fails to consider, that *normative sets* are not static and universal, but stigma is rather "…defined as a process constituted by social life" (Geiselhart 2009:42). In short, these are dynamic processes that are of changeable character, which is underlined by Charmaz who writes that "…labels are attached to the person, but stigma arises in interaction and within relations" (2000:284), hence being dynamic.

The stigma given may lead to possible negative consequences in the form of discrimination: the exclusion of the affected person from greater society. Whether consequences are negative or positive depends on the character of the attribute according to the valid set of standard normalities. If an attribute threatens the security of the majority – as would a contagious disease, a negative reaction is

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[28] Among these are Weiss, Ramakrishna and Somm (2006), as well as Kusow (2004) with his article titled *Contesting stigma: On Goffman's assumptions of normative order.*

more obvious.[29] The attribute imputed does not have to be recognized by the bearer, felicitously categorizing the person affected as a *discreditable* or a *discredited* person (Goffman 1979:56-57).

According to Geiselhart, to actually stigmatize entails a more broad and inchoate sense than discrimination, as it is not directly assigned to one person but rather to abstract themes such as "…beliefs, morals, or social norms" (2009:39). Hence "…stigmatization (…) appears as a matter of *morality* (…) and thus is often regarded as being *beyond the scope of an individual's influence*" (Geiselhart 2009:39; emphasis added, L.B.) – consequently it adheres to logic that a moral evaluation accompanies stigma (Goffman 1979:46).

Stigmatization is rather a matter of cognition, being "…located in the imagination and attitudes of individuals, *not of action*" (Geiselhart 2009:39; emphasis added, L.B.), thus consequences following are not a *must*, thereby alleviating its threatening character to some extent. This might explain why people judged based on any one or many attributes, tend to speak of *stigmatization* rather than use the term *discrimination* while referring to themselves, denominated by Geiselhart as an "avoidance strategy of words" (2009:39).

However, Charmaz insists that "[b]oth enacted and felt stigma [can] contribute to difficulties in preserving prior identity" (2000:286), potentially leading to withdrawal from social relations, and isolating the person in general (Goffman 1979:43).

Kleinman (2011) comments in his lecture on cross-cultural mental health on the negative effects of a stigma on individuals in the context of illness, saying "social rights come only after fulfilling social obligations to the family" – possibly leading to difficulties for a stigmatized individual and in the worst case concluding in "social death" by "social exclusion" (Kleinman 2011:n.p.).[30] He further clarifies his statement in that he provides two options for the stigmatized individual: "The patient may resist the stigmatizing identity, or he may accept it; either way his world has been radically altered" (Kleinman 1988:160).

Goffman famously "…claimed that the 'stigmatized' could not escape the role the 'normals' provide for them" (Geiselhart 2009:46), whereas Goffman (1979) uses the term *stigma* to describe exclusively negative phenomena. In his book *The geography of stigma and discrimination* (2009) Geiselhart is critical of Goffman (1979), advocating that the acceptance of the stigma in general is *not* a consequence of necessity. Furthermore, stigmas and stigmatization are not exclusively negative, but dependent on the viewpoint of the conferrer and carrier.

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[29] Here the stability of the majority society is of great importance. In case the stability is not threatened, a neglect of reaction might occur or even mercy. For further information please see Link (2009:17-39, 109-115).

[30] The videotaped lecture of Prof. Kleinman took place at Freie Universität Berlin on June 28th, 2011 and can be found here: http://www.fu-berlin.de/sites/cas/Video-Ordner/Video_Kleinman/index.html [30.04.2013].

Cases where the person internalizes the experienced discrimination or stigmas they have been assigned are defined as cases of *self-stigmatization*. It may lead to retreat or coping processes by the individual, as the person implores to change the social relevance of the stigma given (Geiselhart 2009:89). This again leads to an alteration of the social role, as well as the surrounding society (Geiselhart 2009:150). When a person shifts from a discreditable to a discredited person, the affected person might discern carefully between what and whom to confide in, fearing possible consequences in form of discrimination and depending on the given stigma. Moreover not only the person bearing the stigma is affected, but the surrounding society might fear a "spread to family and social networks in reciprocal ways" (Kleinman 2011) as well. This fear causes society to react adversely to the stigmatized, avoiding the person and his/her family or friends (Goffman 1979:43; Weiss and Ramakrishna 2006:537). Disclosure can however serve to gather support for the individual from similarly afflicted peers, for example via support groups.

Therefore it can be concluded that an attribute evolves into a stigma in accordance to social and cultural norms and belief systems within groups, and furthermore depends on individual experience, given that "[a]ttributes [again] shape experiences, and experiences in turn shape behavior" (Geiselhart 2009:151). What is *normal* or *abnormal* – or stigmatized – will fluctuate according to the given perspective, and "[s]tigmatizing reactions can vary greatly in the degree to which they are perceived as justifiable, either by the marked person or the marker" (Jones et al. 1984:9).

According to Geiselhart, and in contrast to stigmatization, *discrimination* "…is considered to imply *actions* against deprived people" (2009:38; emphasis added, L.B.) although these actions can be manifold. The verb *to discriminate* derives from the Latin *discriminare*, meaning *to distinguish* (Partridge 1977:826). Hence this already implies a process of action, whereby it has become a term often used in political debates, consequently leading to negative connotations (Geiselhart 2009).

Discrimination can be seen as a possible consequence of deviating from the norm (Goffman 1979:161), being embodied in oneself or a group. Following Geiselhart (2009), *to discriminate* means *acting* against (most often minorities), whereas in contrast *stigmatization* refers to attitudes. These actions infer certain unstatic, negotiable, and changeable social and cultural conditions, such as stigmas themselves.

The action taken thereby reflects moral attitudes of social identity backdrop, whereas it can be

> *"…assume[d] that people diligently try to enhance the image of their own group while they attempt to devalue the other group. As a result, social processes on larger scales tend to create manifest groups that are in opposition to each other"* (Geiselhart 2009:55),

often creating a powerful superior group. Here an "ethnocentristic orientation"[31] (Allport 1971:61) is of great importance while differences need to be preserved, being fed by prejudice and stereotypes.

People experiencing discrimination often tend to deceive themselves, an attempt of self-protection. This is only minimally successful, since individuals consequently confront several restrictions (Goffman 1979:116-117).

According to Goffman

> *"[t]he issue is not that of managing tension generated during social contacts, but rather that of managing information about his failing. To display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case to whom, how, when and where"* (1963:42),

is of great importance for the handling of the personal identity and well-being (Goffman 1979:84).

Finally Geiselhart writes that the cycle of discrimination and stigmatization can be broken, should "…people commit themselves to individuating processes, such as coping on the part of the bearers and piecemeal assessment on the part of the non-bearers" (2009:165). According to Geiselhart (2009) the only way to break through the vicious pattern of stigmatization requires people to meet the stigma with openness.

3.1 Stigmatization and discrimination in the context of illness and disease

Experiences of stigma are often seen in the connection with the appearance of illness and disease – the attributes in question in this publication. As Charmaz states, "[e]xperiencing stigma is a common consequence of chronic illness and a constant threat in some ill individuals' view" (2000:284). Illness and disability elicit "…stigmatizing definitions of difference" (2000:284), therefore possibly leading to distribution of blame, discrimination and stigmatization – hence leading to a *moral career* of the person affected.

Actions of stigmatization and discrimination lead to an emphasis on difference between the person being discredited and the one discriminating. The person being discriminated might feel marked, treated like a lazar, and will try to minimize or conceal indications for being (chronically) sick in order to avoid discrediting views or verbal attacks for example.

As explained in the previous chapter on illness and disease a set of normalities guides social inclusion or exclusion. The majority of a society often feels the urgent need to exclude people marked as *different* – such as the ill – who embody a

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[31] The original citation in German is the following: "Eine ethnozentristische Orientierung ist für sie wichtig" (Allport 1971:61).

threat to the stability of the group. This again explains discriminatory action. The healthy amount to a powerful majority while the visibly sick may not belong to the majority of the group, hence being *abnormal*. Allocation of blame thus serves as an explanation and excuse for discrimination and even gives responsibility for the illness to the affected person.

Depending on the attributes attached to the disease, the need of exclusion seems high in order to keep the societal majority secure. People excluded then consequently have to fend for themselves, hence leading to a loss of power effectively diminishing their threat to the majority.

In her book *Illness as metaphors* (1987) Susan Sontag regards stigma from a "society-focused angle", according to Geiselhart (2009:40). Though the book does not directly deal with stigmatization, Sontag (1987) explains that diseases are often described through metaphors – such as *fighting* a disease – thus generating stigma and discrimination through the language in use. According to Sontag (1987), altering the way in which we stigmatize disease begins with our abandoning of such metaphors, which negatively influence disease perception.

Paula Treichler agrees, although she insists that

> *"[n]o matter how much we desire, with Susan Sontag, to resist treating illness as a metaphor, illness is a metaphor, and this semantic work – this effort to 'make sense of' AIDS – must be done"* (Treichler 1999:15; emphasis removed, L.B.).

Conclusively, illness and disease are and will be described through metaphors. Important is, that we develop an awareness of these powerful perceptions and the way that language works in culture (Treichler 1999:25).

According to Sontag (1987) fear is often a motivating factor for discrimination in the context of disease, especially in the case of incurable infectious diseases and their accompanying symptoms. Additionally, a lack of knowledge concerning disease transmission and the dangers of infection can cause fear. People affected and peers in their immediate environment might then address the topic only behind closed doors in order to avoid discrimination. This secrecy, however, again causes uncertainty and fear. Furthermore, the disease might distance the person from a *normal* life, as daily activities can no longer be performed as usual due to certain restrictions, which may lead to self-stigmatizing definitions of difference.

Segregating an affected person from society, keeping a secure distance and securing social stability is one (discriminative) strategy employed by the healthy. Consequently, negative public prejudices might have a powerful impact on sick people. Interestingly and even though the "… person so labeled is shunned, derided, disconfirmed, and degraded by those around [her/]him" (Kleinman 1988:160), this discrimination is often absent among immediate family members (Kleinman 1988:160).

3.2 Stigmatization and discrimination in the context of HIV and AIDS

Regarding the impact of HIV and AIDS globally, it may be reasonable to compare the disease to the once devastating infectious diseases of the last century, whose threat has diminished in the era of antibiotics. For instance with Lepra, it was common to segregate the infected individual and to disinfect and clean every belonging to prevent further infection. Similar behaviors are documented in reaction to the HIV pandemic worldwide, as it is perceived as a highly infectious and incurable disease (Sontag 1987, 1989), therefore uncontrollable in nature and often connected with immoral behavior.[32]

The medieval plagues were understood as diseases due to moral uncleanliness, for which a society sought a scapegoat[33] within their community (Sontag 1987:85). Especially the mode of infection through sexual activity is rife with social and moral perceptions. Consequently this leads to questions of blame in the context of HIV and it is implied that the sick person is devalued and at fault for contracting the disease (Charmaz 2000:284).

Consequently the expression of the disease through symptoms might lead to theories of its origins and modes of infection. This again leads to "…perceptions of an impure (local and/or social) environment, which seems to advance the infection with the disease"[34] (Dilger 1999:3). As McElroy and Jezewski put it, diseases like HIV and AIDS "…do evoke concepts of moral responsibility" (2000:196). And according to Green "[p]eople with HIV who were infected sexually (…) are thus particularly vulnerable to 'victim-blaming'" (1995:557), while "…the victim [is blamed] in the ideology of personal life-style change" (Kleinman 1988:21).

Thus identifying a scapegoat might liberate the society of the responsibility to search for explanations.

While in New York City in 2011 I listened to a conversation about HIV with people I had encountered incidentally. It was on a rooftop, where we happened to meet a couple of young, highly fashionable and self-confident men of Manhattans Lower East Side. While talking about music a friend I was accompanying

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[32] HIV symptoms develop late, then suddenly hit the person with devastating AIDS symptoms, finally leading to a fatal outcome. In this context and because of incurability and symptoms the question of disclosure without a mark or visibility of the disease is one of importance and serves as a trigger for the distribution of a stigma and the subsequent active discrimination (Goffman 1979:67).

[33] For etymological explanation and origin of the term scapegoat please see Allport (1971:251-253).

[34] The original citation in German is "…formt sich die Vorstellung einer unreinen (lokalen und/oder sozialen) Umgebung, die die Ansteckung mit der Krankheit zu fördern scheint" (Dilger 1999:3).

mentioned the famous rapper Eazy-E[35] and later said: "Well … you know what he died of?" A short silence followed until the young men started giggling and one of them said: "Oh yeah. He died of AIDS. He was just *doing it* with too many dirty women!" and the others agreed, laughing.

This encounter clearly underlines the perceived social connection of HIV with dirtiness and moral damnability, which can be found all over the globe.

In general AIDS-related stigma "…refers to prejudice, discounting, discrediting, and discrimination directed at people perceived to have AIDS or HIV, and the individuals, groups, and communities with which they are associated" (Herek 2009:n.p.). Fear plays an important role in the decision people make to radically confine themselves from infected individuals. It is an attempt to consequently protect *oneself* from stigma and discrimination.

The severe consequences experienced by people living with HIV/AIDS (PLWHA) are many, such as "…rights, freedom, self-identity and social interactions, and may have psychopathological consequences" (Green 1995:558).

A total of 51 countries have passed restrictions on the entry, stay or residence of HIV-seropositive people, among them India and Australia (UNAIDS 2010a:127). People infected might not be allowed to travel to or stay at length in these countries. This can be perceived as highly discriminatory against people infected with HIV, however countries enforcing the law may argue that protection of their people is of greater importance than freedom of any one individual – raising the question on how legislation like this is legitimized.

In general, legitimation for an action can be seen and its validation judged very differently. According to John Stuart Mill's dictum (1869) the freedom of the individual shall have its limits in the freedom of the group. But when is it justifiable to exclude or restrict a person from a free life just for having an infectious disease? Where should the line be drawn?

HIV-seropositive people are not only restricted in their freedom to move freely but in countless decisions concerning their lives. Recently cases of HIV-seropositive women involuntarily being sterilized in South Africa, Namibia and Chile were reported in the media, legitimizing sterilization in order to avoid pregnancy and birth to further possibly HIV-seropositive children[36] (Nair 2010) – a clear violation of human reproductive rights.

This leads to an ethical debate in which answers and solutions given by individuals, societies, countries, carriers, and non-carriers certainly differ. In this case again fear is a crucial driving force.

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[35] For further information please visit the website in remembrance of Eric Wright (Rap Basement n.d.) at http://www.eazy-e.com/eazy_e-biography.php [09.05.2013].

[36] For further information on this topic please read the article written by Ray (2010) and visit the website of *The International Community of Women Living with HIV/AIDS* (ICW) (International Community of Women Living With HIV/AIDS 2009) and *The Body* (2010). Moreover the article by Nair (2010), as well as from GlobalPost (Bonnefoy 2010) can be recommended.

The HIV infection and AIDS are loaded with stigma and people infected face a high degree of discrimination. According to Dilger, stigmatized attributes exist naturally in the form of societal prejudices based on conceptions of normal and abnormal and are just now being discussed and explored in HIV discourse (1999:4), while "AIDS-related stigma [thus can be seen as] (…) a socially constructed reaction to a lethal illness" (Herek and Glunt 1988:886).

In the western world, the disease is still particularly ascribed to drug injection users, male homosexuals and prostitutes, belonging per se to a minority subject to much prejudice (Green 1995:557; Herek and Glunt 1988). In contrast, in Tanzania HIV was long seen as a disease of the rich, Americans, or of whites in general (Dilger 1999:4-7), shrouded in mystery.

According to Treichler, AIDS will remain confined to the original high-risk groups, as these perceptions protect the "…heterosexuality's ideological superiority…" (1999:20), automatically leading to possible isolation of the person affected (Sontag 1989:27). On the contrary, as expressed by Geiselhart "[t]he perceptions and interpretations of HIV and AIDS have altered tremendously over the last few years and the last milestone was the introduction of the ARV therapy" (2009:48). This statement reflects the ever-changing perceptions of the disease (Geiselhart 2009:40) and therefore criticizes the rigid model of normative expectations constructed by Goffman (1979:156-160) especially in the context of HIV and AIDS.

But still the infection of HIV is most often seen as sexually transmitted and therefore infection is often attributed to a misstep by the infected person (Sontag 1989:28). In this sense, the question of blame in HIV-infection is easily addressed.

3.2.1 Stigmatization and discrimination in the context of HIV and AIDS in Tanzania

Countless authors have given general attention to HIV related stigma and discrimination.[37]

In Tanzania stigmatization and discrimination in the context of HIV are widespread.[38] Many people in Tanzania are unwilling to undergo an HIV test, as surveyed by the UNDP (2010), due to stigma and discrimination in the context of HIV and AIDS. According to UNICEF in Tanzania

> *"[s]tigma and discrimination are still widespread among Tanzanian adults, according to the 2007-2008 'Tanzania HIV and Malaria Indicator Survey'. Some 43 per cent of women and 35 per cent of men surveyed reported that they would not buy fresh vegetables*

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[37] Amongst others are Brimlow, Cook and Seaton (2003), Brown, Trujillo and Macintyre (2001), Castro and Farmer (2005), Herek and Glunt (1988), Herek and Capitanio (1999), Herek, Capitano and Widamann (2003) and Herek (2009).

[38] The most recent are Augustsson and Forsberg (2006), Grimm (1997), Kisinza et al. (2002), Nyblade et al. (2003) and Zou et al. (2009).

> *from a shopkeeper who has HIV, and 51 per cent of women and 41 per cent of men would keep it a secret that a family member is infected with the HIV virus [sic]"* (2010:n.p.).

Which factors influence the development of this highly stigmatized disease, leading to discrimination in Tanzania? In the following pages a brief abstract of the uncountable factors contributing to this high degree of stigmatization and discrimination in Tanzania will be presented here, although the listing given can only be incomplete.

In their study, Amuri et al. (2011) concentrated on people stigmatizing in Tanzania and *first* revealed that particularly people living in poverty, having a lower educational level and being located in rural areas have a highly stigmatizing attitude. As shown by MEASURE DHS (2005:205) over 99 percent of the urban population interviewed has heard of AIDS, whereas levels of education and residency had a significant impact on the knowledge concerning transmission (MEASURE DHS 2005:208). On the contrary only 29 percent of people with no education had comprehensive knowledge on HIV. It may be hypothesized that there does exist a causality of low educational level, discrimination, and prejudice regarding HIV and AIDS.

Secondly HIV is known as a deadly disease, thus far incurable and often perceived as highly contagious. Although exact numbers of how many people know somebody living with HIV or that has died of AIDS are unknown, due to a high prevalence rate one might assume that a majority of Tanzanians have been confronted with the disease. Therefore personal experiences with the disease and the associated death might lead to a general fear and the urgent need of separation, distance and attention to difference, looking for a scapegoat – most often excluding the infected individual from the societal majority.

Thirdly, the most common mode of transmission in sub-Saharan Africa is publicly taught by international organizations and believed to be heterosexual intercourse (UNAIDS 2010a:30), therefore laying the groundwork for a connection to immoral behavior, such as adultery and prostitution. As Kleinman concludes, "…AIDS brand[s] the victim with the painful (and in the case of the latter, deadly) stigmata of venereal sin" therefore "…bring[ing] particular cultural meaning to the person" (Kleinman 1988:21). However, not only international organizations but religious institutions and belief frames are opinion-leading and influence "…the daily behaviors and attitudes of many people living in countries with high rates of HIV/AIDS" (Zou et al. 2009). Especially churches play the role of a moral authority, preaching against promiscuity before marriage and violations of such religious teachings are seen as a sin. Consequently, infected youth may be particularly vulnerable to discrimination.

Fourthly a "…language of 'attack' and 'defence' common in virology and AIDS awareness discourses…" (Ashforth 2010:50; emphasis in original) has become commonplace. HIV and AIDS – as once with cancer - are commonly transported in connection with a military like terminology, also identified by Sontag (1987:77).

The war like language is especially prevalent within the mass media, politics, and most often campaigns dedicated to HIV prevention. As such, patients and society are said "to fight", or "to combat" the disease,[39] and the disease is seen as a "perpetrator" or "enemy", the infected patients are christened "victims", while an AIDS fatality is equated to "losing a fight" (GIZ n.d.a:n.p.; PEPFAR n.d.:n.p.; UNDP 2010:n.p.; The Citizen 2010b:n.p.). The language used has potential influence on the societal perception of the disease, possibly leading to an AIDS related phobia (Treichler 1999:25). The patients on the other hand may also as a result integrate the disease into their daily life until the disease and the *fight* against it become a personal attribute. In this context Sontag (1987) claims that the disease needs to be linguistically demurred. A more neutral point of view and discussion must replace the language of fear and enemies.

Finally in Tanzania the governmental reaction to the disease was initially one of retention. HIV and AIDS was a "…distasteful subject to mention in public" (Iliffe 2006:66), while politicians distanced themselves from the disease and avoided addressing the issue. According to Augustsson and Forsberg, this is still common among the political elite, since they fear "…the large impacts it could have on their power as well as on the constructed order of the society" (2006:39). A few significant exceptions exist, notably Aaron Chiduo, Tanzania's Minister of Health, who publicly addressed the topic of HIV and "…who insisted that 'Law can never succeed to control the disease. We must concentrate on persuasion'" (Iliffe 2006:66)

Last but not least as once the case with cancer, the contraction of HIV is still understood as a death sentence, thus an HIV diagnosis may lead to taciturnity and even denial. Affected people tend not to talk openly about their disease, fearing discrimination. The surrounding society also remains silent, aiming to protect the person affected, as well as themselves. Thus a frank openness concerning HIV is lacking. Though people in Tanzania do talk about the disease, it is often paraphrased and talked through *dalili*[40] (signs), while often orienting on "…indigenous concepts of taboo infringement, sorcery or spiritual bedevilment…" (Dilger 2005:283).[41]

Reasons again are manifold, although especially in the context of HIV people tend not to talk about it openly, as it has an "obscene" (Sontag 1987:11) and taboo character. People most often fear blame for contracting the disease while

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[39] For further information please see the *Millennium Development Goals for health* (MDG 6) and the multiple progress reports, which can be found on the website of the United Nations (2010) at http://www.un.org/millenniumgoals/aids.shtml [30.04.2013].

[40] The Kiswahili term *dalili* was frequently used by Halima referring to her perception of illness (Interviewee 56, Section 08, 142 and 154).

[41] The original citation of the German sentence is the following: "…indigenen Konzepten von Tabubrüchen, Hexerei, oder Geistbessenheit" (Dilger 2005:283).

"…HIV/AIDS may be perceived as bringing shame on the family and the community as a whole" (Augustsson and Forsberg 2006:12).[42]

In conclusion, people with HIV and AIDS all over the world often confront stigmatization and discrimination. A combination of several factors in Tanzania contribute to this, such as the character of the disease as invisible, incurable and deathly, the common perceptions of the mode of infection through sexual intercourse, shameful silence, and lastly terminology in use borrowed from a military context.

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[42] The thesis written by Augustsson and Forsberg (2006) and theories stated – especially concerning highly generalized sexual roles in Tanzanian society – strongly need to be questioned, possibly laying the path for prejudice and discrimination itself.

4. HIV & AIDS

Within this chapter biomedical facts regarding the HI-Virus and the clinical manifestation of AIDS will be presented. Knowledge of basic facts allows for a better understanding of the disease from a biomedical standpoint and its impact on the individual and society at large. Additionally the history and myth of origin as well as the international and Tanzanian governmental response will provide depth to the setting in which the study procedure took place.

4.1 Biomedical facts regarding the disease

The Human Immuno-Deficiency Virus (HIV) causes the Autoimmune Deficiency Syndrome referred to as AIDS,[43] a deadly syndrome that makes an individual susceptible to multiple diseases and finally leads to death. So far two different major strains of the virus, HIV-1 and HIV-2, have been identified as well as multiple sub-types. HIV-1 is responsible for AIDS as it is known today, whereas HIV-2 is less virulent and therefore less infectious, mostly found on the West African coast[44] (Iliffe 2006:4; Peeters, Toure-Kane and Nkengasong 2003). The virus belongs to the group of the retroviruses, while its genome is being transcripted into another kind of nucleic acid in the affected cell of the host, before being integrated in the genome of the host cell with the host cell producing viral components.

Especially so-called T1-lympohzytes are inhabited by the virus, responsible for the production of antibodies for the immune defense. The virus hosts itself in the T1-lymphozyte cells, making them ineffective and begins to replicate viral components. The virus can be identified in bodily fluids, with blood seen as the main source for infection, for example through micro-injuries during sexual intercourse, (involuntary) hollow needle sharing or mother-to-child-transmission during pregnancy and delivery. Six to nine weeks following infection, an individual may suffer from a common cold or swollen lymph nodes, a reaction by the immune system to the virus. The virus then replicates and some years later the immune system fails to inhibit so called opportunistic infectious diseases caused by infectious agents (bacteria, viruses and mycotic particles), which the immune system of a healthy subject could easily handle.[45]

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[43] For further information on the discussion of name giving please see Treichler (1999:30-31).

[44] For further information on the HI-Virus please see Iliffe (2006:4-9).

[45] Common among HIV-seropositive people are pathogens especially causing diseases among people with lowered immune system, such as Pneumocystis jiroveci, causing a life threatening pneumonia, Tuberculosis or Herpes Zoster. Furthermore distinct forms of cancer caused or enhanced by viruses can be found. However the virus itself is causing different medical

As of yet, no cure or vaccine has been found (Peeters, Toure-Kane and Nkengasong 2003:2547), although preventive medical kits are in use, which must be taken within ≤ 72 hours of exposure (Smith et al. 2005).

Therapy in form of antiretrovirals (ARVs) either directly affect the virus or the enzymes needed for the replication cycle. The availability of antiretroviral therapy (ART) has proved effective in significantly delaying the deadly outcome of the disease. Unfortunately the HI-Virus has a high mutation rate and may eventually stop reacting to certain ARVs.[46]

4.2 HIV and AIDS – myths and facts on its development

The disease was first consciously recognized in the 1980s,[47] when testing procedures for HIV finally became available (Iliffe 2006:3).[48] Since May 1984 the biomedical viral etiology of the disease is understood (Treichler 1999:25). At about that time the disease started to spread rapidly: a mere two decades later it had grown into a recognized pandemic.

Although the origin of HIV is still unknown, "[the] initial response to HIV/Aids was commonly [and still is] to blame Others [sic]" (Iliffe 2006:80). Myths of origin are manifold. Some trace the origin of the virus to the African continent[49] (Iliffe 2006:4; Treichler 1999:29), whereas "…many Africans believe that AIDS may have originated somewhere else" (Treichler 1999:29). People were always blamed, although responsible parties varied.

> *"Immigrants and refugees from other African countries were widely held responsible. Villagers blamed townsmen. Elders blamed the young. Men and women blamed one another. Everyone blamed sex workers, …"* (Iliffe 2006:80-81).

The fourth chapter of Sabatier's book *Blaming others: prejudice, race and worldwide AIDS* (Sabatier 1988:35-50), entitled *Origins of AIDS, origins of blame*, perfectly demonstrates, that the myths surrounding the origin of HIV are an automatic

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conditions as diarrhea or dementia and or organic psychiatric disorders via affecting the brain, as well as a multifactorial cachexia.

[46] For further information on infectious diseases in general please see Part 7, Section 1 and on HIV and AIDS please see Part 7, Section 2, Chapter 124 of *Harrison's principles of internal medicine* (Fauci 2008).

[47] Although according to Iliffe the pathogen could already be verified through frozen specimens from equatorial Africa dating back to 1959 (Iliffe 2006:3).

[48] Prior to 1983 HIV infections were known but not possible to be identified as such (Treichler 1999:25).

[49] Although until today the origins are highly contested, according to Iliffe strong indications exist, that the HI-Virus is originated in Cameroun or the Democratic Republic of Congo being related to the so called *simian immunodeficiency virus* (SIV) (Iliffe 2006:4). For further information please acknowledge Chapter 2 of his book *The African AIDS epidemic: A history* (Iliffe 2006:4), and Chapter 9 (Iliffe 2006:4). On the contrary, the Los Angeles Times launched an article in 2007 tracing the origin of the HI-Virus back to Haiti (Chong 2007).

attempt to attribute blame and advance prejudices against groups possibly affected.

According to Iliffe and his experiences on the African continent, some see the disease as "'the white man's burden'" (2006:80-81), underlined by Dilger's (1999) observation of the origin of HIV among the Luo in Tanzania, where white people are often thought to be responsible for the origin and spread of the disease. Another common theory claims that Americans developed the virus. And another widely held belief among the Luo is that HIV and AIDS is caused by white men forcing a girl to have sexual intercourse with a dog for money (Dilger 1999:7-9).

4.3 Facts on HIV and AIDS and the international response

In 2009 around 33.3 million people globally were estimated to be infected with HIV, as the *UNAIDS Report of the global AIDS epidemic* shows (UNAIDS 2010a:21), with about 2.2 million new infections in 2009. In sub-Saharan Africa alone about 22.5 million people were estimated to be HIV-seropositive in 2009, comprising of about 40 percent of all adult women infected with HIV (UNAIDS 2010a:28) and there were approximately 1.3 million AIDS-related deaths in 2009 (UNAIDS 2010a:20). These numbers are impossible to fathom, highlighting the enormous impact of the disease.

Remarkably the World Health Organization (WHO) "…did not officially acknowledge AIDS as a global health problem until late 1986" (Treichler 1999:25) and the measures taken by international and national organizations were often considered ineffective, as strategies most often concentrated solely on specific minorities, such as male homosexuals (Iliffe 2006:65).

A cholera epidemic hit Tanzania in 1972, leading to over 5,000 deaths (Mandara 1991:5) and political spheres commonly chose to deny the feared and already stigmatized disease AIDS (Iliffe 2006:65).

Iliffe writes that the first official AIDS conference took place in Atlanta and Brussels in 1985. Following this conference the WHO classified HIV as a major health concern (Iliffe 2006:68). The so-called *Global Programme* was set into action by Jonathan Mann (Iliffe 2006:69). He not only contributed greatly to the establishment of the program but also advocated for the prevention of discrimination against infected individuals.

> *"…the isolation of those found HIV-positive (…) would not only breach their human rights but would deter people from seeking medical care, endanger the healthy, and accelerate the epidemic"* (Iliffe 2006:69).

Even though his argumentation met criticism for its supposed eurocentricism (Iliffe 2006:69), the prevalence rate of HIV-infected individuals relentlessly increased.

According to Iliffe it was only

> *"[i]n the early 1990s [that] several international agencies – World Bank, UNICEF, UNDP, European Union, and others – established their own AIDS policies and programs, bypassing what they saw as the WHO's ineffectiveness"* (2006:79).

Today countless governmental and non-governmental organizations are involved and united in the aim to contain the pandemic and the time of disillusion.

In 2009 the budget for AIDS response was around 15.9 billion US$, 88 percent of the budgets for disease prevention in low-income countries[50] is financed through international funding, with the U.S.A. being the largest international donor (UNAIDS 2010a:43). The sub-Saharan continent alone "... accounted for 57% of total bilateral aid flows for controlling HIV/AIDS in 2004 - 2005 ..." (WHO 2008:10) – Tanzania belonged to the top ten recipients. In 2009 the total funding for dealing with HIV and AIDS in Tanzania alone comprised over 80 percent of foreign funding, mainly supported by the Global Fund and the U.S.A. governmental organization PEPFAR (TACAIDS 2010a:xi), which provides a total of over 400 million US$ in aid (TACAIDS 2008a:viii).[51] Hence most prevention programs rely on international funds.

4.4 The history of international and governmental response to HIV and AIDS and the present situation in Tanzania

In 1982 Oppermann[52] worked at the Department of Internal Medicine at *Bugando Medical Centre* in Mwanza, Tanzania. During his work he came across an article from 1981 in the *New England Journal of Medicine*, reporting a noticeable incidence of infection caused by opportunistic pathogens and lymphoma among young homosexuals in New York City and San Francisco.[53] Decades later, armed with the knowledge of HIV and AIDS, he would have recognized exactly the same symptoms in his patients in Mwanza.

The first AIDS cases were officially reported from Kagera (in western Tanzania) in 1983 (MoHSW - NACP 2007:1), yet it took until 1985 for AIDS to

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[50] UNAIDS (2010a:272) hereby refers to the definition of the World Bank defining a low-income country by income of 1005 US$ or less per capita income within a country, using the 2010 gross national income index per capita (The World Bank 2011:n.p.).

[51] For further information please visit the website of TACAIDS (2008c) website at http://www.tacaids.go.tz/ [07.05.2013].

[52] Prof. Martin Oppermann is dean of student affairs concerning quality management and concerns of Erasmus students, as well as spokesperson of the commission for medical doctoral theses at the Medical Faculty at Göttingen University.

[53] Personal conversation and Email contact with Prof. Dr. Martin Oppermann (17.11.2010; 2.05.2011; 25.04.2013).

become a notable disease in Tanzania. According to the *Ministry of Health and Social Welfare* (MoHSW) and the *National AIDS Control Programme* (NACP) health authorities throughout the country were then obliged to report AIDS cases to the ministry (MoHSW - NACP 2007:1).

Initially, the MoHSW dealt with HIV by itself. In 1985 the *National Task Force* was founded, including members of organizations and different institutions. Soon the *National AIDS Control Programme* (NACP) was launched[54] in an attempt to control the disease, supported by the WHO's *Global Programme on AIDS*. In 1987, the MoHSW had already received reports of over one hundred AIDS-cases in Tanzania. The *Ministry of Health* then took action, launching *voluntary counseling and testing* (VCT) programs throughout the country, and by 1997 a total of 59 sites had been established in 19 regions (MoHSW - NACP 2007:1).

In the following year people infected by HIV and people suffering from AIDS were given the necessary general medication and treatment in governmental hospitals free of charge (The United Republic of Tanzania 1998:29; cited in Dilger 2005:21).[55]

In 1999 the *Tanzanian Commission for AIDS* (TACAIDS) stated that

> *"HIV/AIDS has now become the primary cause of death among adults in the country and is decimating the most productive age group leaving behind misery, suffering and poverty. HIV/AIDS epidemic is a big social and economic problem with devastating impact on national development"* (2008b:n.p.).

Following this statement, the President of the United Republic of Tanzania, Mr. Benjamin William Mkapa, declared in 1999 the HIV epidemic a "national disaster" (TACAIDS 2003:v) and called the epidemic "... an extraordinary crisis that requires extraordinary measures to deal with…" (TACAIDS 2008b:n.p.), calling for a multi-sectoral response.

Two years later, in 2001, TACAIDS was founded in order to fulfill a strategic and organizational role. In 2002 the first *Prevention of Mother to Child Transmission* (PMTCT) programs were launched by the Tanzanian government, with support from UNICEF.

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[54] The NACP is operating until today, having multiple offices throughout the country, among one of them on the compound of the Bombo Regional Hospital in Tanga city at the time of research conduction in 2008, supporting the research project throughout the conduction and beyond.

[55] Although the Tanzanian government appears active it often fails to implement successful programs. As Dilger (2005:21) states and as personally experienced, people are either often uninformed about the existence of such programs or patients attempting to access such offerings are confronted with corruption rampant in hospitals throughout the country, such as paying with *chai* (tea) in order to receive prompter treatment.

It was in late 2003 that HIV – after first data surveys – was constituted an epidemic in Tanzania,[56] leading to a budget increase from 17 billion TZS to 381 billion TZS for HIV and AIDS prevention between 2001 and 2007.

The Tanzanian government responded, and in 2004 the widespread distribution of ARVs through hospitals and faith-based organizations grew in 22 facilities in nine regions throughout the country. Further *Care and Treatment Centers* (CTC) were developed within national health facilities, more than doubling in number to 200 CTCs with a total enrollment of 125,139 patients, of whom more than half were women (The United Republic of Tanzania 2010:3; MoHSW - NACP 2007:52).

Affiliated VCT Centers, built to perform HIV-testing also developed quickly. By 2003 a total of 289 sites were offering VCT, expanding to 1,027 sites in 2006, "managed by public and faith-based organizations" (MoHSW - NACP 2007:1), with 45 sites under the management of the *African Medical Research Foundation* (AMREF), and the affiliated *Angaza Project* (MoHSW - NACP 2007:1).

By 2006 testing for HIV was possible in 98 percent of all hospitals and 64 percent of all health centers either governmental or privately owned (WHO 2008:10).

Finally, after multiple studies concerning their effectiveness and the dissolution of patent rights, ARVs began to be available in African countries starting in the late 1990s.[57] In Tanzania they were initially only available at pharmacies and received through relatives abroad and in 2004, health facilities throughout the country began distributing the medication (Iliffe 2006:138-157; TACAIDS 2009:3). According to UNAIDS

> *„[t]he effects of antiretroviral therapy are especially evident in sub-Saharan Africa, where an estimated 320 000 (or 20%) fewer people died of AIDS-related causes in 2009 than in 2004, when antiretroviral therapy began to be dramatically expanded ..."* (2010a:19).

As of 2010 the number of people on antiretroviral therapy (ART) in Tanzania is around 345,000 (TACAIDS 2010b), but still only approximately one third of the people in need receive ART (UNAIDS 2010a:111, 2010b:30).

In 2007, Tanzania's president Kikwete launched the popular and so called *National HIV and AIDS Campaign* – a mobile *Voluntary Counseling and Testing Center* (VCTC), which traveled for a year throughout the country offering HIV tests free

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[56] In 2004 the *Ministry of Educational and Vocational Training* (MoEVT) conducted a survey stating that by the year of 2020 about 27,000 teachers will be lost to AIDS. A worrying analysis especially since the teacher's profession is one of the numerical highest in Tanzania (TACAIDS 2009:4).

[57] Multiple combinations of various ARVs are now available in western countries, while combinations of treatment lines in Tanzania are limited. The availability of ARVs has risen the life expectancy of people infected nearly to that of non-infected people.

of charge, resulting in the testing of over four million people (TACAIDS 2009:1-9).

Since the first registered HIV-cases in 1983 the prevalence of HIV has steadily increased, peaking in 1993 at 8 percent. Today the prevalence has stabilized at 6 – 7 percent, although – according to UNAIDS-ASAP – a second rise in disease prevalence is likely in the future (UNAIDS-ASAP 2008:4).[58]

In 2009 an estimated 1.4 million people were living with HIV in Tanzania (UNAIDS 2010a:111) – of whom approximately 730,000 were women over 15 years of age (UNAIDS 2010a:182) – with some 88,000 new infections occurring (UNAIDS 2010a:185). Although the death rate is decreasing in Tanzania, approximately 1.3 million children in 2009 had already been orphaned (UNAIDS 2010a:111).

The rate of new HIV infections among adults in Tanzania has decreased (UNAIDS 2010a:184), as well as the number of people infected with HIV (UNAIDS 2010a:19,61). Whether this is due to increased knowledge on HIV and AIDS, the successful implementation of ART,[59] or to increasing deaths due to AIDS remains to be seen.[60]

4.5 The international and Tanzanian political response to stigma and discrimination in the context of HIV and AIDS

Numerous countries have reported the existence of laws and regulations aimed to protect PLWHA, although data is lacking concerning their enforcement. As awareness of discrimination and stigmatization rose, it was accompanied by a remarkable increase in existence of legislation against discrimination in the investigated countries from 56 to 71 percent since 2006, although only 56 percent of the countries included had the capability to survey discrimination.

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[58] For further information on prevalence trends in Tanzania please consult the UNAIDS report entitled *The HIV epidemic in Tanzania mainland: Where have we come from, where is it going? And how are we responding? - Final report* (UNAIDS-ASAP 2008) and the *HIV/AIDS/STI Surveillance report. January - December 2005. Vol. 20.* (MoHSW-NACP 2007:1).

[59] Appropriate treatment is discussed to not only reduce the viral load but the probability to infect others through sexual intercourse. A large clinical trial, which will be conducted by the *National Health Institute* until 2015, is proving the assumption and recently provided affirmative results of an interim review of the data (National Institute of Allergy and Infectious Diseases 2011).

[60] In general, statistics and numbers should be considered with caution and not automatically accepted as solid fact. The figures presented here should serve for a better understanding, although one may argue that the numbers are biased due to competing interests of several stakeholders. According to Treichler "[i]n Africa, "underreporting" is taken for granted and estimates are corrected upward; at the same time, the number of positive cases actually diagnosed may be too high or too low, depending on the procedure used" (1999:113-114).

> *"Despite reporting of an increase in protective laws, there is little evidence whether these laws are effectively enforced or whether people living with HIV and other people key in the response have access to justice or can seek redress for wrongs experienced"* (UNAIDS 2010a:128).

Although levels of stigma and discrimination are difficult to measure, especially as the meanings of attributes might overlap, and exact and comparable definitions are lacking, according to UNAIDS-ASAP (2008) there has been significant reduction in the level of stigma and discrimination.

In Tanzania in 1992 "…32% males and 18% females felt that AIDS patients should be quarantined or put in jail" (UNAIDS-ASAP 2008:27). However, a survey demonstrates a decrease in discrimination, as over 89 percent of people surveyed would be willing to care for an HIV-seropositive patient at home (MEASURE DHS 2005:214), compared to 79 percent in 1996 (UNAIDS-ASAP 2008:27). In this regard, it can be hypothesized that discriminatory attitudes are decreasing.

In 1992 Tanzania made official first mention of the problem of discrimination and stigma in the context of HIV (Augustsson and Forsberg 2006:33), but it was not until 2008 that the country passed a law "[p]rohibiting stigma and discrimination against PLHIV, especially in the workplace" (USAID 2008:2; UNAIDS 2010b).

This law prohibits the stigmatization or discrimination of persons "…on the grounds of such person's actual, perceived, or suspected HIV and AIDS status" and asks

> *"…[g]overnment, political, religious, and traditional leaders and employers in the private sector to advocate against stigma and discrimination of people living with HIV and AIDS…"* (USAID 2008:7).

The law may be a step forward, however as noted by AVERT (2011:n.p.), "…sufficient training on the reforms for those who implement the law and public awareness of the rights included is needed for the law to be effective".

4.6 "…this problem faces every family – in one way or another…"[61] – Dealing with HIV and AIDS in Tanzanian society

The following shall serve as a brief overview of the general perception and handling of HIV and AIDS in Tanzanian society, putting special focus on Tanga

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[61] Interviewee Neema (Interview 06, Section 54). For further information please see chapter 7.2.2.

city[62]. To be sure, generalizations and broad interpretation were necessary due to a lack of literature and data in order to obtain deeper insight into the context of HIV in Tanzania. Therefore the generalized conclusions drawn are largely based on personal experience and observation.

Walking through the streets of Tanga city, HIV has perceptibly presence in town. Male and female models advertising for *Salama Condoms* smile broadly from visible road signs or posters.[63] Support groups for PLWHA place hand painted boards next to the road and occasionally the red ribbon icon[64] is visible – a symbol originally meant to show solidarity for people infected by HIV, now a general symbol for HIV and AIDS (see Figure 1).

Figure 1: Road sign in Tanga city. Below it is written in Kiswahili *UKIMWI unaua*, meaning *HIV and AIDS kills you* (Mattes 2011).

Condoms can be obtained in Tanga city at nearly every kiosk, dangling from their ceiling and available at bars[65] and are also distributed by NGOs as well as in a

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[62] Here it is differentiated between the terms Tanga city (Kiswahili: Tanga mjini), Tanga District and Tanga Region.

[63] For a vivid impression please see figure 4 in the book *Besser der Vorhang im Haus als die Fahne im Wind – Geld, AIDS und Moral im ländlichen Tansania* written by Dilger (1999:20).

[64] For further information on the red ribbon please visit the website of the organization called *Red Ribbon Deutschland* (n.d.) at http://www.redribbon.de/rr/Home.html [09.05.2013].

[65] Please see Agha and Meekers (2004) for further information and who studied the availability of social marketing interventions of condom distribution, as well as the availability of condoms. It was found that "[c]onsistent with the project's goal to make *Salama Condoms* accessible to low-income populations, there was a significant increase in availability at non-traditional outlets, such as retail shops, kiosks, street vendors and wholesalers" (Agha and Meekers 2004:138).

wooden applicator at the BRH entrance for free. However, most of the time the boxes were (already) empty when I passed by the entrance while leaving the hospital compound in the early evening.
Especially in urban Tanzania HIV and AIDS constitutes a well-known disease among the public, although "[s]till less than 50% of young men and women in the country have knowledge about HIV infections and precisely reject major misconceptions about HIV" as a Tanzania population based survey showed (The United Republic of Tanzania 2010:23; UNAIDS 2010a:83).

Information concerning HIV and AIDS is available from radio and television media, churches, discussions with neighbors and friends, or from the newspaper. Strikingly at the time of Dilger's research in Tanzania, all of his interview partners knew people who have died of AIDS (1999:28), as implied by Neema, one of the interviewees presented, who said "…this problem (HIV and AIDS) faces every family - in one way or another…" (Interview 06, Section 54).

Drawing on personal experiences in Tanzania, people tend to talk about HIV and AIDS, but use a highly secretive and careful manner – these experiences were also shared by Mogensen in Uganda (2010:63). Reasons for this are manifold and especially dependent on the position and the environment of the person talking. I personally listened to conversations at the hospital compound and in the neighborhood, where people tend to discuss the disease and unknown infected individuals in a very general way, carefully keeping a deliberate personal distance from the disease. HIV and AIDS is strongly associated with moral failure and death, therefore constituting a general threat and – due to its discriminating nature – automatically leading to a question of blame connected with the assumption of an unmoral lifestyle.[66]

As described by Sontag, it is common that reasons for disease contraction are often connected with having committed a crime (Sontag 1989:48). Dilger has hereby experienced a silent debate on "indigenious concepts of braking taboos" (2005:238)[67] in Tanzania: AIDS is often seen as a symbolic punishment from God in a society tinged with a highly moral discourse (Dilger 1999:43).

There are many reasons to speak carefully about HIV when talking to infected people or their immediate entourage, mainly to maintain hope and care for the infected individual (Mogensen 2010:67-69), and to prevent a possible early outbreak of the disease by discussing it, as well as to protect a person by averting discrimination and stigmatization (Dilger 2005:328).

However, my general impression is that people in Tanzania talk more openly about HIV and AIDS and discussions are more vivid since the availability of free ARVs, compared to in 2002. Mogensen supports this impression, stating

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[66] On this point please see Chapter 1, *AIDS-Forschung zwischen Stadt und Land: Konzeptuelle und methodologische Implikationen*, in the book titled *Leben mit AIDS* (Dilger 2005:49-93).

[67] The original German citation is the following "...indigenen Konzepten von Tabubrüchen" (Dilger 2005:283).

> *"[w]hat is said about the disease and people who are infected and how it is said have changed over the years, and it is reasonable to assume that antiretroviral treatment will bring yet other changes in how AIDS is talked about in the public sphere as well as in the local moral worlds and everyday social interactions"* (2010:62; referring to Kleinman 1995).

When talking about HIV and AIDS the common term in use is *UKIMWI,* an abbreviation in Kiswahili for *ukosefu wa kinga mwilini* meaning *deficiency of protection in the body* (Dilger 2005:313). Nonetheless many other words for HIV are in use[68] as shown in the interviews analyzed, such as *miwaya*[69] (wire) and *ngoma*[70] (music, drum, vagina). Additionally synonyms to describe the actual mode of infection are used such as *kunawa*[71] (to wash), *msaada*[72] (help or assistance) and *umeme*[73] (lightning, electricity).

The use of *ngoma*, a slang word for vagina, directly associates and accuses the woman as the primary carrier of the infection. An association experienced by Dilger stating that "…mostly specific subgroups of the population – [and] often women (…) are seen as indicators of (…) moral ruptures" (2010:10), therefore constituting "moral fault-lines" (2010:10).

Miwaya or *kukanyaga miwaya* (to step on wire), as well as *umeme* on the other hand are Kiswahili metaphors in use, which may implicate a sudden injury mainly caused through inattention, therefore averting the allocation of blame. In addition, interviewees attributed their infection to time spent caring for other HIV patients or for patients in whom the virus was later found, using the words *msaada*, as well as *kunawa*, specifically diverting the blame for their own illness.

All of these are metaphors for the disease or the mode of infection, allowing the listener to interpret as he or she so chooses, averting direct blame through purposeful methaphorical language.

In sum one can say that HIV and AIDS is an overall present disease especially in the urban Tanzanian society. Although discussed, conversations are still held in a careful manner, especially by a person with close or direct contact to the disease, using multiple metaphors. On the one hand a person talking about HIV might want to avert direct association with the disease; on the other hand people seem to try to maintain hope to the person affected, as HIV is often directly associated

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[68] An overview of slang words in Kiswahili used for HIV and AIDS and the infection with HIV is given by Cornice (2011) and can be seen at the following website http://mwanasimba.online.fr/slang/E_slang_16.html [08.05.2013].

[69] Neema used this word referring to HIV (Interview 06).

[70] Mentioned by Elisa (Interview 27).

[71] The word was mentioned in the context of HIV and AIDS in all interviews presented here.

[72] Mariamu (Interview 03), Amina (Interview 11), Rose (Interview 14), and Halima (Interview 56) mentioned the word in the context of HIV.

[73] Neema (Interview 06) and Halima (Interview 56) used the word referring to HIV.

with a death sentence, anticipation of AIDS and lingering illness.[74] Whether one will observe measurable changes in conversation due to the availability of ARVs remains to be seen.

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[74] For further information please see Ashforth's discussion on the topic of stigma in the context of HIV with groups of VCT counselors in South Africa (2010).

5. The Research Study

The results presented here are the partial results of a multi-method cross-sectional research study, conducted at the Care and Treatment Center (CTC) of the *Bombo Regional Hospital* (BRH) from March to September 2008.

Objectives of the main study were to explore rates, patterns and barriers to verbal HIV-serostatus disclosure[75], partial disclosure and non-disclosure among HIV-seropositive women attending the CTC and further to explore decision-making and experiences in this context. Additionally special attention was given to pill taking and investigation of reasons for (non-)adherence to ARVs among HIV-seropositive women. Finally we questioned the women regarding their possible past or current participation in therapeutic alternatives.

Although the results presented in this book are embedded into the research study described above, the following chapter solely contains information provided in order to better understand the partial results presented here. In the following sub-chapters information on the research setting and conduction of the research will be presented.

5.1 The research setting

The United Republic of Tanzania is divided into 26 regions, which are split into multiple districts. The population is remarkable due to its ethnical diversity, including Tanzanians of Arabic, Indian, and Pakistani origin. With more than 120 ethnic groups and separate languages, Kiswahili has become the national language. Although the national census has not included a question regarding religious affiliation since 1967 (The Citizen 2010a:n.p.), "Tanzania's population has been estimated to consist of roughly one-third (each) [of] Muslims, Christians, and followers of indigenous religious groups [respectively]",[76] and additionally Buddhists and Hindus (The Citizen 2010a:n.p.). In urban areas of Tanzania the majority of adults (57,6 percent) have visited primary school between 5th and 8th grade, in contrast to a quarter of the Tanzanian population with no education and nearly one third being illiterate (National Bureau of Statistics Tanzania 2002:7). Over one third of the population lives below the

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[75] The term *disclosure* was defined as *the verbal disclosure of the HIV-seropositive status to a third party*. We hereby differentiated between *voluntary* and *involuntary* disclosure or *not applicable* to the terms mentioned, as well as fully disclosure (disclosure to everybody possible), partial-disclosure (disclosure to selected people) or non-disclosure (no disclosure to anybody).

[76] The definition of indigenous beliefs in the data presented here is missing, as well as religions such as Buddhism and Hinduism. Numbers presented therefore need to be questioned.

poverty line of basic needs, with an average consumption of 10,000 TZS per person per month (National Bureau of Statistics Tanzania 2002:4).

The Tanga Region with its 1.6 million inhabitants (The United Republic of Tanzania 2011a:n.p.) is located in the northeastern most part of Tanzania bordering Kenya and the Indian Ocean, whereas Tanga city builds the municipal council of the Tanga District (The Citizen 2010a:n.p.) with over 242,000 inhabitants (The United Republic of Tanzania 2006:15).

Tanga city is a picturesque and calm seaport, though being one of the biggest cities in the country. The German colonial era is still apparent through the Cliff Block – a ruin and former German hospital –, the clock tower, and the German cemetery. At the time of research the city was only mentioned as a minor point of interest in travel guides and therefore of minimal interest to tourists.

The town itself is divided into multiple areas, such as the Bombo area around the hospital, Raskazone – a neighborhood mainly inhabited by the wealthy – and Ngamiani with bustling market streets, where shops are mostly managed by people of Arabic and Indian ancestry. Tanga's industry consists of several businesses such as a cement factory, tea-, soda-, and sisal-production, as well as dairy products.

Among Tanzanians the Tanga District in general is very popular for the power of its traditional healers (*mganga kwa kienyeji*),[77] and their herbal medicine (*kwa dawa za mitishamba*) and spiritual power (*kwa ramli*) and people from all over the country come to Tanga seeking cure.[78]

With eleven hospitals in the region (Ofisi ya Mkuu wa Mkoa wa Tanga 2008:n.p.), numerous health dispensaries, and two private hospitals in Tanga city alone, the BRH is the main and leading university teaching hospital, providing biomedical treatment to a population of more than 243,000 people in Tanga city (The United Republic of Tanzania 2011b:1).

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[77] For further translations please visit the online English-Swahili Dictionary (TshwaneDJe - Software and Language Services 2011) at http://africanlanguages.com/swahili/ [09.05.2013].

[78] According to the National Bureau of Statistics about 5.5% in urban areas and a total of 15% of the total Tanzanian population on the mainland visit traditional healers (2002:11). For further information please see the book written by Mackenrodt titled *Swahili spirit possession and Islamic healing in contemporary Tanzania* (2011).

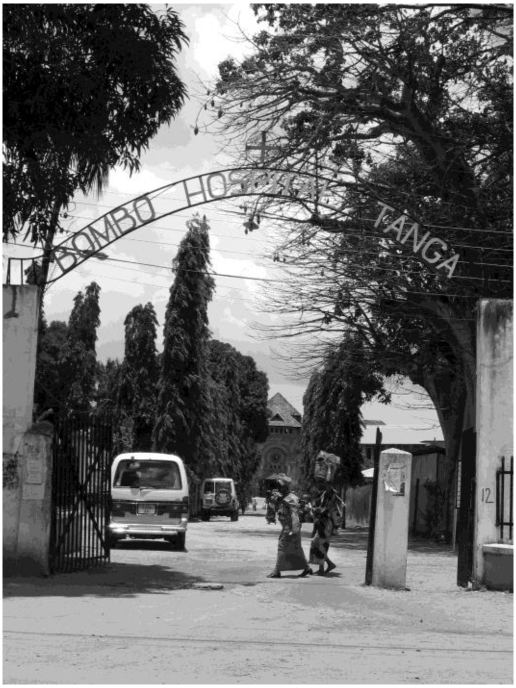

Figure 2: Entrance of Bombo Regional Hospital with Cliff Block (Personal photo, 2008).

In pursuance of several work related visits and experiences gained at the BRH in Tanga city in Tanzania between the years of 2002 and 2006, the BRH was chosen as the research location (see Figure 2).

The HIV Department, which was dedicated in June 2006, consists of a CTC, VCTC, a specialized pharmacy, and laboratory, and is embedded into the hospital complex as an independent department (see Figure 3).[79]

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[79] At the time of testing at the VCTC people were given information on HIV and AIDS. In case of a positive test result they were asked to disclose to at least one person, accompanying him/her at their first visit to the CTC. An appointment was given and the health status of the infected was checked. In case of the commencement with ART, patients had to attend three adherence classes, resulting in being personally *tested* of their knowledge gained, before receiving ARVs.

Figure 3: Care and Treatment Center of Bombo Regional Hospital (Personal photo, 2008).

The staff includes several AMOs[80], special trained nurses, pharmacists, and data clerks. Remarkably, data clerk statistics indicate that more than twice as many women as men were registered patients at the department.[81] Interestingly, during my research I personally noted no official Tanzanian patients with noticeable Asian or Arabic ancestry at the CTC.[82]

The department was dedicated with the financial and logistical support of AIDS Relief,[83] distributing ARVs free of charge (see Figure 4). However PMTCT and *highly antiretroviral treatment* (HAART) was already implemented at the hospital in June 2005 with support from the *Ministry of Health and Social Welfare* (MoHSW).[84]

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[80] Assistant Medical Officers (AMO) have undergone special health care courses, in hierarchy being in the position between a Clinical Officer and a Medical Officer, able to provide curative and preventive services, as well as conducting minor operations (Pemba 2008:1).

[81] The information was given during an informal interview by an anonymous source (29.7.2008) in Tanzania and confirmed by an anonymous source through Email on June 21, 2011.

[82] Reasons therefore can only be conjectured. As the social cohesion between the different ethnic groups seems to be strong, Tanzanians of Asian or Arabic ancestry might either visit hospitals lead by people of the same ethnic belonging or might visit private hospitals as they are often having greater means due to involvement in business located in the formal sector.

[83] For further information concerning AIDS Relief please visit the website of *The U.S. President's Emergency Plan for AIDS Relief* (PEPFAR) (Office of U.S. Global AIDS Coordinator and the Bureau of Public Affairs n.d.) at http://www.pepfar.gov/ [09.05.2013].

[84] Information is based on a personal conversation with Selemani Msangi, the Regional AIDS Control Coordinator of Tanga Region (10.10.2007).

Figure 4: The department floor of the CTC at Bombo Regional Hospital (Personal photo, 2008).

During data collection the department opened at 8:00 a.m., and soon was crowded with people. They sat on wooden benches, talking, often patiently waiting for hours to be called for consultation. Endless queues with sometimes up to nearly 200 patients per day were seen by the few AMOs in charge, went for testing, attended adherence classes or had their CD4-lymphocyte count[85] checked. Still more came to pick up their monthly ration of ARVs. At around 4:00 p.m. usually the last patient left the department.

5.2 Preparations and conduction of the research study

From August to October 2007 and prior to commencement of the research study, I visited the Bombo Regional Hospital in Tanga, Tanzania and the CTC. During the visit government representatives, researchers, and employees in the

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[85] The term CD4 refers to the abbreviation of *cluster of differentiation 4*. The CD4-lymphocyte count is used as a surveillance parameter as this cell-line is specifically affected by the HI-virus with a low CD4-count meaning a high probability of opportunistic infectious diseases and other AIDS defining disorders.

field of HIV and AIDS were met, further information revealed about the current situation concerning HIV in Tanga District and my expanded understanding of the hospital structure allowed the clarification of important logistical questions.

The planned social scientific research project was then introduced at the daily hospital meeting visited by all leading hospital staff and the Regional Medical Officer (RMO) of Tanga Region joined as the local partner of the project.

In addition, the *German Technical Cooperation* (GTZ) with its *Comprehensive Multisectoral AIDS Control Sector* was acquired as a cooperation partner, supporting the project organizationally, including the provision of staff for the project, office space at the BRH site as well as technical equipment.

Financial support came from a DAAD scholarship and the Gö4Med fellowship of the Medical Faculty of Göttingen University in order to realize the project fully.

Finally the study was conducted from March to September 2008. First, all people involved in the research project were introduced to the research, followed by a thorough preparation of the project realization on site.

Two female Tanzanian interviewers[86] were employed as well as two Tanzanian translators for translating the transliterated interviews from Kiswahili into English.[87]

Interviewers were trained for three weeks, familiarizing themselves with the project, its goals, the tasks of an interviewer, the methodology of interviewing, and appropriate reaction to unexpected emotional reactions by the participants.[88] Clearance and consent forms, questionnaires and guideline-interviews were translated into Kiswahili and discussed with the staff of the research study.

After training of computer skills and special software for transliteration of recorded interviews, transliteration rules were set and instructions had to be written and practiced. Furthermore translators were trained, learning the transliteration rules.

The project was then introduced to all hospital staff from the CTC and VCTC as well as the pharmacists from the CTC department and written consent in order to conduct participant observation at the CTC/VCTC site was obtained from all staff after elucidating the staff thoroughly, delivering a clearance form to all hospital staff.

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[86] It was made sure, that all staff employed for the research study had not been employed by the BRH in the past. Additionally it was ensured that interviewers were female Tanzanians, fluent in English and Kiswahili and not previously involved in the work with HIV and AIDS patients to secure subjective questioning during interview sessions.

[87] Non-medically trained interviewers were consciously chosen in order to avoid a too directive mode of questioning. It was also of great importance to employ female interviewers to ensure a comfortable and intimate interview condition for the women interviewed.

[88] For further information on training of interviewers please see Hermanns (2007:367-368).

Finally a suitable interview room in the corridor of the CTC department was found, securing enough privacy for the participants being interviewed and furnished accordingly.

AMOs, fluent in English, were asked to recruit the female HIV-positive participants for the study in accordance with our recruitment rules and received recruitment training as well as a training concerning the questionnaire prior to the study conduction.

A total of five AMOs were employed by the BRH at the CTC during the time of research, with an average of two doctors being present during the busy consultation hours during which the patients were recruited.

After recruitment patients were invited to come to our interview room located at the same floor of the CTC department.

The period of interview taking with the HIV-seropositive women was conducted for a total of three months, wherein a total of sixty-one interviews were held. The interview sessions were conducted twice daily, three days a week.[89]

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[89] At the end of data collection preliminary results were presented at two separate meetings to the director of BRH, the Regional Medical Officer and local partner of the study, all hospital staff and the GTZ members. A second meeting was organized and preliminary results were presented to all patients interviewed, who were willing to attend.

6. Methodology

As this book is dealing with the topic of stigmatization and discrimination in the context of illness and disease experienced by HIV-seropositive women in Tanga, the methodology of the research study conducted relevant for the topic dealt with, will be explained in the following chapter.

The methodology chosen will be described, including the selection of women interviewed and the recruitment process, as well as the protection of study participants. A short overview of the research design will be given, before explaining the methodological combination in use, such as questionnaires and ethnographic methods. Finally data processing and data analysis will be described.

6.1 Study participants and recruitment process

A total of 61 (n=61) HIV-seropositive female patients of the CTC participated in the study[90] of which six outstanding interviews were chosen for presentation according to the criteria of informative interviewees and personal rating of particular significance in the context of the main topics presented in this book.

The inclusion of exclusively female participants in the study had different reasons. First, more than 4000 women were enrolled at the CTC in the year of 2008, comprising more than twice the number of men.[91] Therefore recruitment of women was an organizational advantage. Second, and according to Farmer and Kim (1996), women are particularly vulnerable to contracting HIV,[92] which encourages special emphasis on women.

> *"In cities throughout the world, and in certain rural areas as well, complications of HIV disease have become the leading cause of death of young women. Poverty and gender inequality are two reasons why the fastest-growing epidemics are among women,*

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[90] Due to the topic of verbal disclosure and possible non-disclosure, and in order to secure confidentiality, interviewees had to be recruited in the hospital. The HIV-seropositive women interviewed hence belonged to a special category, already being tested positive for HIV, being enrolled at the CTC, having undergone pre- and post-counselling, as well as adherence classes in order to be eligible for receiving ART. It therefore needs to be considered that the women presented here do not represent all HIV-seropositive women in Tanzania.

[91] The information was given during an informal interview by an anonymous source (29.7.2008) in Tanzania and confirmed by an anonymous source through Email on June 21, 2011.

[92] According to the *UNAIDS Report on the global AIDS epidemic* from 2010 women in sub-Sahara Africa between the age of 15 to 24 are "…eight times more likely than men to be HIV positive" (UNAIDS 2010a:10). While "[p]rotecting women and girls from HIV means protecting against gender-based violence and promoting economic independence from older men"(UNAIDS 2010a:10).

> *who in some regions of the world already constitute the majority of those infected"* (Farmer and Kim 1996:xiv-xv).

In Dilger's words, women are more vulnerable to HIV infection "…due to their societal position, which is culturally, politically and historically fixed, often leading to an interdependence towards men"[93] (2005:31).

AMOs received written instructions and recruitment rules in English and a questionnaire for the participants every day of recruitment. One doctor was randomly chosen daily to recruit two patients for the study and received his/her working sheets by the data clerk.

The first female patient matching all recruitment criteria[94] was chosen by the AMO after having visited the ambulatory consultation at the CTC to voluntarily participate in the study, receiving a short elucidation.

6.2 Clearance, consent and confidentiality

Ethical permission from the Ethical Committee[95] of the Medical Faculty of Göttingen University was successfully obtained, as well as Ethical Permission from the Ethical Committee of the *National Institute of Medical Research* (NIMR) in Tanzania[96], and research permission from the *Tanzanian Commission for Science and Technology* (COSTECH)[97].

The study was performed according to the *Declaration of Helsinki* (The World Medical Association 2008) while people involved in the study procedure, such as interviewers and translators, were informed of the study procedures and had to give written consent to secure confidentiality before commencing their work.

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[93] The original citation in German is the following "…auf Grund ihrer gesellschaftlichen Position, die kulturell, politisch und historisch verankert ist und die Frauen oft in ein Abhängigkeitsverhältnis zu Männern stellt, besonders verletzlich für eine Infektion mit HIV" (Dilger 2005:31).

[94] General inclusion criteria were being a female HIV-seropositive patient enrolled at the CTC, tested positive earliest at the last time visiting the CTC, being in a stable (not sick) condition to undergo a questionnaire and an interview of approximately one hour, and being at least 18 years of age. General exclusion criteria were a low mental health status, not able to be interviewed, less than 18 years old and not having given verbal and written consent. The doctor, additionally using the patient's file, therefore proofed listed criteria.

[95] For further information please visit the website of the Ethikkomission of Göttingen University (Universitätsklinikum Göttingen 2010) at http://www.ethikkommission.med.uni-goettingen.de [30.04.2011].

[96] Please visit the following website of NIMR (National Institute for Medical Research n.d.) for detailed information http://www.nimr.or.tz [30.04.2011].

[97] Please visit COSTECH (2013) at http://www.costech.or.tz/ [08.05.2013] for further information.

At the time of recruitment patients were asked to give verbal consent to the doctor. Before commencement of the study procedure in the interviewer room patients were read aloud a clearance and consent form in Kiswahili, of which they received a copy. The interviewer then verbally informed participants about the research procedure by the interviewer. Patients were asked to give either written consent by signature or alternatively by using an ink fingerprint before being questioned and observed. The individual participant was informed that withdrawal from the study was possible at any time – meaning that all information gained so far would be completely destroyed, and that all information would be saved anonymously, with taped audio data restricted to the interviewer and those responsible for the study.

Patients were offered a snack while being interviewed but no money was offered in order to guarantee voluntary participation. Nor were doctors recruiting the patients offered money in order to secure voluntary participation of the patients asked. After finalization of the research study doctors did unexpectedly receive a monetary compensation provided by the GTZ in recognition of their work.

All material collected during the research period was saved with a standard encryption software, ensuring anonymity and stored in a safe.

In order to secure anonymity each of the women presented here has been given a pseudonym and further data presented within this book was fully anonymized, with the numbers behind the interviewees to indicate the chronological order of all interviews taken.

6.3 Research design

For this study the approach known as *triangulation* on the level of methodology, data analysis, investigators chosen[98] and multidisciplinary approach was used (McElroy and Jezewski 2000:204). A quantitative and ethnographic research design was chosen, including a choice of six adapted standardized guideline-interviews, as well as participant observation during the interview, supplemented by two different questionnaires beforehand.

No invasive or any other medical interventions were requested or performed in the context of the study at any time.

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[98] For a detailed exploration on the topic please consider the book *Triangulation: eine Einführung* written by Flick (2008), as well as Flick (2007:309-318).

6.3.1 Questionnaires for HIV-seropositive women

After recruitment of the patient and verbal consent, the doctor completed a short questionnaire in English using consultation information from the patient's file, providing demographic and health-related information such as date of first HIV-test, marital status, and age, taking about two minutes.

In the interviewer room another pre-tested interviewer administered questionnaire in Kiswahili was conducted, containing a total of 34 questions read out by the interviewer due to a fairly high illiteracy rate[99] among Tanzanian women, taking about ten minutes. Due to the interview setting in Tanzania the questions had to be designed and adapted accordingly.[100]

The questionnaire focused mainly on demographic data, verbal disclosure, and adherence to ART. In light of the responses, the interviewer could then immediately summarize and expand upon data evaluated in the questionnaire in the subsequent interview.

6.3.2 Ethnographic qualitative methods

Multiple methods are believed to better serve the studying of personal experiences on illness, and the consequences arising, as well as the behavior attached to it.

As argued by Margaret Lock and Vinh-Kim Nguyen, ethnography is a possible method "[g]iving voice to peoples without power whose opinions and experiences are rarely heard or known…" (2010:9) and allows "…revealing entanglements among (…) cultural values in connection with the global circulation of biomedical technologies" (2010:10). As within this research study a specific topic within a specific field[101] was investigated, one can refer to the term *focused ethnography*[102] used by Knoblauch (2001:123).

Interviews took between twenty to sixty minutes, while an average of 48 standardized open-ended questions were asked. The interview session was voice recorded using a standard MP3 player with voice record function.

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[99] The literacy rate is about 66% among women between the age of 15 years and above in Tanzania in the year of 2007 (Karolinska Institutet, Division of Global Health 2011:n.p.). Noticeable, women from rural settings of Tanzania mainland show a significantly lower literacy rate of 58,1% of the age of 10 years and above according to the Census conducted in 2002 (The United Republic of Tanzania 2006:56).

[100] For designing the questionnaire the *Allgemeine Bevölkerungsumfrage der Sozialwissenschaften* (GESIS 2011; Eirmbter and Jacob 2000) could not be used as preconditions in Tanzania - such as the school system – differ tremendously. Hereby the design of the questionnaire was based on Braun (2006).

[101] The research study concentrated on verbal disclosure and adherence to ART among HIV-seropositive women at the VCT/CTC of Bombo Regional Hospital.

[102] Knoblauch refers to the term *fokussierte Ethnographie* in German (2001:123).

Methodological emphasis was placed on participant observation during the interviews conducted by the principal investigator of the study, in form of a *moderate participation* (Spradley 2009:59-60). The aim was to document the behavior of the patient while being interviewed and the interaction between the interviewer and the patient.[103] As stated by Kleinman in reference to participant observation, "[t]he facial expression, tone of voice, posture, body movements, gait, and, especially the eyes, expose the emotional turmoil that is so much a part of the long-term experience of chronic illness" (1988:44), therefore providing important information about their life and illness experience.

6.4 Processing of data material

Interviews were transliterated by the interviewer using the open source audio-editor software Audacity 1.2.6a (n.d.) and the audio-transliteration software F4 for Microsoft Word (Dr. Dresing & Pehl GmbH n.d.). Transcription rules designed by Kallmeyer and Schütze (1976), cited by Mayring (1993:66) and Kuckartz (1999:62) were used, although slightly modified.

After proofreading, transliterated interviews were translated from Kiswahili into English by two independent translators fluent in both languages. Afterwards translations were again proofread to secure validity of the translation conducted. The content was discussed with the interviewer on a weekly basis throughout the study.

As suggested by Rosenthal (2008:112,115), observations were simultaneously paper-documented, while focusing on differentiation between interpretations and actual observations without valuation and finally typed accordingly the very same day.

6.5 Data analysis

Interviews were analyzed, using the structural content analysis, as defined by Flick (2007:473). Before final coding, the first ten interviews of the pool of n=61 were coded and a code guideline was designed.

As the book concentrates on the topic of discrimination and stigmatization in the context of illness and disease the topic of disclosure was not analyzed here in

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[103] For general information on PO and information on the historical development of the technique of participant observation please see Rosenthal (2008:101-105) and Lüders (2004:222-224). For further information of possible criticism and challenges in the context of documentation please read Rosenthal (2008:110-111), Lüders (2004:227-230) and Bloor (2008:182-183).

particular although it was mentioned within the results where applicable and necessary.

After definition of main categories (=codes), such as *illness, disease, discrimination and self-stigmatization*, further sub-categories were established, in particular by creating so called *in-vivo codes*, using terms verbally directly extracted from the interviews (Kuckartz 2005:70).

Sub-codes were then deduced from main codes, such as the differentiation between different forms of discrimination. Especially in the context of discrimination, sub-codes were again categorized and it was distinguished between general knowledge (GK), self-experience (SE) and a separate third category, not being applicable to the two mentioned before, named *none of the above* (NA).

Kuckartz differentiates between three different categories of codes, hereby referring to so-called *fact-codes,* guaranteeing objectivity (2005:94).[104] Finally, coded material was paraphrased and summarized by reduction of material "…through selection, deleting or bundling of codes" (Lissmann 2001:71). [105]

For a better overview of data collected, the text analysis program MAXQDA Version 2 for Windows XP was used (VERBI GmbH 2010), employing thematic coding according to Kuckartz (2005:85-94).[106]

Definitions of the terms *discrimination*, as well as *self-stigmatization* were used for coding, adhering to Geiselhart (2009). *Discrimination* is therefore an attribute given to bearers by non-bearers, regarded as a distinction, which can lead to different treatment of the bearer. In contrast, *self-stigmatization* "…occurs when a bearer of a stigma[107] themselves trigger the assessment of their attributes as being a stigma" (Geiselhart 2009:154) leading to a possible overestimation of "…the importance of prejudices and stereotypes and are tempted to refrain from committing themselves to a process of coping" (Geiselhart 2009:154).

In Kiswahili it is differentiated between the terms *to stigmatize* (kunyanyapaa/kunyanyasa) and *to discriminate* (kubagua). While the verb *to stigmatize* is often used in the context of HIV and AIDS, *kubagua* also means to segregate/to separate, although in the context of discrimination women interviewed explicitly referred to discriminating actions. According to the definitions provided by Geiselhart (2009), the Kiswahili terms used in the

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[104] According to Kuckartz (2005:97) only limited literature is published concerning the procedure of coding. For further information please see Kuckartz (2005: 92-100).

[105] The original citation in German is "…Reduktion durch Selektion, Streichung oder Bündelung…" (Lissmann 2001:71).

[106] For further information on the development of computer text analysis please read the chapter titled *Computer text analysis* written by Krippendorff (2008:12-15).

[107] For a definition of the term stigma used by Geiselhart, please check *Box 4: Short explanations about stigma and discrimination* (2009:154).

interviews will be replaced by the applicable terms as defined above in brackets behind the words in the cited interview.

The code of *illness* was defined as the lived experience of the person being sick and suffering as described by the women, while *disease* was defined as a deviation from the state of normality, while the patients were translating their complaints into technical terms of a particular healing system.

Before final coding an independent coder coded the first ten interviews using MAXQDA and results were discussed, in order to ensure inter-rated reliability of the codes (Flick 2007:471) and optimization of the code guideline in use.

Using the final code guideline all chosen interviews were coded again. Coded interview material concerning the statements of the patients was then analyzed,[108] compared and the frequency of categorical systems served as a basis for verifying the impact of self-stigmatization and discrimination in the context of illness.

For further characterization of the subjects demographic data (age, religion, educational level, level of income and ethnic belonging) from the questionnaire was analyzed, using the statistic analysis software SPSS 15.0 for Windows (IBM Company n.d.), with all figures rounded up to two decimal places.

Last but not least relevant data of participant observation was manually extracted to provide an illuminating image of the women interviewed.

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[108] For further information please see Döring and Bortz (2003).

7. Results

In reviewing the results, all data from the statistically analyzed questionnaires will be provided to give the reader an overview of the study population and demographic data in comparison to the interviews chosen for detailed analysis, ensuring an objective selection of the Tanzanian population and the complete study sample.

A short summary of each woman interviewed follows, drawing a picture of each interviewee and allowing the reader to better immerse into the statements provided by the women presented.

Finally snippets of the coded interview results will be presented. To maintain a coherent picture, the results of the interview analysis will be organized by categorizing the results thematically according to the codes ascribed, such as *illness* and *disease*, as well as *self-stigmatization* and *discrimination*.

7.1 Results of the questionnaire – quantitative data

The mean (± standard deviation, SD) age of all 61 women being interviewed is 38.75 years (SD ±7.99 years) whereas the mean age of the women whose interviews are analyzed here is higher with 43.83 (±11.39). However, independent t-test did not reveal a significant difference of the subjects whose interviews are not analyzed here in contrast to the ones examined (data was normally distributed for both groups (one sample Kolmogorov-Smirnov Test not significant) and was equally distributed (Levene's Test for Equality of Variance not significant); t=-1.66, df=59, p>0.10).

The mean (±SD) amount of money per household[109] per month of each women interviewed is 124,381.82 Tanzanian Shillings (TZS) (±466,794.84) whereas the average amount of money per household available and analyzed here is 683,333.33 (±1402403.90) TZS with the high SD pointing to one extreme outlier with an amount of money per household and month of 3.5 million TZS. An independent t-test with Levene's test for equal variances revealed an unequal variance due to the woman's high amount of money per household. When corrected for this unequal variance no significant difference of the groups could be observed (t = -0.995, df = 6.003, p=0.358).

With the interview of this woman being analyzed the two groups were not significantly different (data was normally distributed for both groups (one sample Kolmogorov-Smirnov Test not significant) and was not equally distributed

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[109] A household was defined as a group of people sharing common living arrangements.

(Levene's Test for Equality of Variance significant, statistical values were corrected); t=-1.00, df=5.00, p≥0.36). When the extreme outlier was excluded from analysis mean (±SD) amount of money per household per month was 61,830.37 (±5,5055.65) TZS for all subjects and 66,000 (±40,987.80) TZS for the analyzed subgroup. The results roughly match the average monthly income per household in urban areas of Tanzania mainland with 103,000 TZS and of households receiving their income with agriculture of 51,800 TZS (The United Republic of Tanzania 2000:127) and a medium income of 77,400 TZS.

All 61 women interviewed belong to a total of twenty different ethnic groups, with the *Sambaa* being the most frequent. Due to the high number of different ethnic identities no adequate statistical test could be identified to compare the whole sample to the sample whose interviews were analyzed. Furthermore no comparison could be made to the total population concerning the ethnicity of the total population in Tanzania as no data is collected at the national population census. Notable is that none of the subjects whose interviews were analyzed belonged to the *Sambaa* ethnic group, which, together with the *Digo*, is the most frequent of the Tanga Region. [110]

In the Tanzania mainland population approximately 30 percent subscribe to the Christian religion and 35 percent are Muslim (Central Intelligence Agency 2011)[111], although personal experience estimates percentage of affiliates of Islam in Tanga city to be much higher. Most of the interviewed candidates were Muslim (n = 40) and thereby Islam was the most frequent religion of the analyzed sample (n = 6).[112]

As with ethnicity no adequate statistical test could be found to check for possible differences. However, depicting the frequencies one can assume no relevant differences between the two groups.

In Tanzania a total of 55 percent of females 25 years or older have ever attended school (The United Republic of Tanzania 2006:68), while 36 percent completed upper primary school and only 0,3 percent upper secondary school (The United Republic of Tanzania 2006:69).

The majority of the women interviewed visited primary school,[113] the second largest group reported having no school education. No adequate statistical test

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[110] See Table 1: Ethnic belonging of participants.

[111] According to the website of the *Central Intelligence Agency* (CIA) (2011:n.p.) the other 35% refer to indigenous beliefs. Unfortunately the definition of indigenous beliefs is missing, as well as religions such as Buddhism and Hinduism – percentages are therefore questionable.

[112] See Table 2: Religious belonging of participants and Diagram 1.

[113] The Tanzanian school system comprises of seven years of primary school, followed by four years of secondary school and an additional two years of secondary school allowing students to take the A-level exams. After thirteen years of school one can take the Advanced Certificate.

could be found to check for possible differences of the group whose interviews were not analyzed and the group whose interviews were analyzed, although one can assume from the data analyzed and compared to the average female population that women without any school education may be underrepresented in the selection. [114]

In sum the statistical analysis comparing the selected interviews presented in this study with the total of 61 interviews conducted shows a well-balanced study group concerning mean age and mean amount of money per household per month. The analysis concerning the school education may show an underrepresentation of the women in the study with no schooling.[115] Reasons for a possible underrepresentation may be a greater acceptance of participating in the study by women with formal education, as well as the urban catchment area of the research setting.[116]

7.2 Images of the women interviewed

Before revealing the further interview results an image of each woman interviewed will be presented, including her social situation and HIV-testing experiences, providing a vivid characterization of the person behind the results.[117] Information was retrieved from notes taken during participant observation during the interview sessions, from questionnaires and interviews.

Examination, allowing students to continue further studying at university level (Mwenegoha 2011).

[114] See Table 3: Level of school education of the participants and Diagram 2.

[115] A total of 30.1% of the population of the Tanga Region have never attended school (The United Republic of Tanzania 2006:66).

[116] Although no statistical analysis could be found presenting differences in attendance of school among females comparing urban to rural settings, a literacy rate among women of the age of 10 or above in urban areas of 84% and rural areas of 58,1% shows a significant difference in education levels (The United Republic of Tanzania 2006:56).

[117] Where direct citations of the interviews conducted have been presented, they were slightly modified where appropriate in order to ensure a fluent reading. While brakes and side noises noted were deleted where applicable, no words said have been omitted. Where passages were omitted a curly bracket was used, where passages were added for a better understanding or explanation round brackets were used. For explanations of words in use round brackets including an equal sign were used.

7.2.1 Mariamu

Mariamu[118] was one of the first women to be interviewed. When she entered the interview room her hair was covered by a piece of black fabric of the *Buibui*[119], a popular dress for Muslim women in Tanga city, loosely bended at her neck. Additionally her head and shoulders were covered by a black-brownish sliding *Khanga*[120], showing her decent stud earrings occasionally. Underneath the Khanga she was wearing a dress of red fabric, on her feet she had basic red rubber flip-flops.

She stored her little black handbag carefully on the table next to her and while sitting on the chair vis-à-vis the interviewer, both arms rested on the table. During the whole interview she listened carefully and attentively, asking questions and gesticulating from time to time.

Mariamu is a married woman, forty years of age, and has three children who have not yet been tested for HIV. She was married in a religious ceremony to her husband, is Muslim, belongs to the *Pare*[121] ethnic group and lives in Tanga city.

At the time of interview Mariamu told us that she currently lives with her biological parents as she had moved out of her husband's house.[122] She explained the reason for moving back to her parent's home by saying that she was "causing

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[118] Interviewee 03.

[119] A Buibui is a chador, often worn by Muslim women in Tanzania. It is mostly made of black polyester fabric, designed as a mixture of a loose dress and a cape without any zipper or buttons. It is normally worn on top of a dress, having long sleeves and reaching down to the floor covering the ankles. Some of the Buibuis are soberly decorated by rhinestones along the sleeves and neckline. At the time of research conduction the Buibui was a very popular and fashionable dress among young women in Tanga city.

[120] A Khanga is a typical piece of fabric in Tanzania worn by the women and used for multiple purposes. It is a long piece of fabric, with the same design printed on it twice. Normally it is cut in the middle into two pieces, having two identical pieces at the end and preferably sewed at the cutting lines. It is then worn covering the head (most often loosely, whereas one corner is often thrown onto the shoulder of the other side), as well as tied around the waist on top of a skirt or dress.
Typical for a Khanga is the slogan printed onto each piece of the fabric and which makes it possible to differentiate to a Kitenge. The Khanga is chosen according to the saying, not according to the color or design printed on it. While Khangas serve as gifts amongst others for marriages, births, deaths, welcoming gift or farewell, they serve multiple uses, such as carrying a baby, protecting your face by covering it due to dust and dirt on the road, tying up your money or using it as a bed sheet in the hospital.

[121] The *Pare* ethnic group comes from the area of *Same*, near Moshi at the Kilimanjaro Region in the very North of Tanzania.

[122] A situation also experienced by Dilger, conducting research in the Mara Region. Here husbands send their HIV-seropositive wives back home "…to their families of origin to be cared for and die" (Dilger 2010:118).

pain to her husband", though she mentioned that she is physically separated from her husband rather than emotionally.

As a child she visited primary school until seventh grade. For her income she sells soap, which is a popular business among women in Tanga. This allows her to support her household[123] of nine with an average total monthly income of approximately 40,000 Tanzanian Shillings (TZS).[124]

She reported that her first voluntary testing took place at *Makorora Health Center* in Tanga city during her pregnancy, as she felt continually ill. She was then asked to test again after delivery and completion of the forty days ceremony[125] at Bombo Regional Hospital, where she presented herself with her sister, referring to one of her good friends.

The reactions she experienced following disclosure were numerous. When she disclosed the result to her husband "... he did not agree to it and he was totally against it ... I did not feel good ..." (Mariamu, Section 08).

After the second test at Bombo Regional Hospital she again told her husband and he answered

> *"... 'you should not tell anyone (i.e. about your HIV status)!' Then I wondered this problem (i.e. HIV) is crucial nowadays. If I wont tell anybody I might get other problems anytime. When I went home I told my brother, my sister, and my young sister ..."* (Mariamu, Section 181).

And Mariamu told us "... until now my husband does not believe that I am infected do you understand? But we talk and laugh …" (Mariamu, Section 234).

Following her diagnosis she began taking herbal medicine from *Tanga AIDS Working Group*[126] (TAWG) until she started with ARVs from BRH as her CD4 dropped heavily.

The VCT staff advised her in revealing the disease and when she partially shared the result with some people she experienced both positive as well as

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[123] The average household size in mainland Tanzania comprises 5,7 persons per household (The United Republic of Tanzania 2000:123).

[124] As 1000 Tanzanian Shillings were about 0,46 Euro at the time of interviewing, Mariamu and her household have an average income of about 18 Euro per month.

[125] After giving birth a forty-day period begins, where the woman stays in the house, being taken care of by the relatives. After these days a ceremony takes place, meeting up with people having tea and *Maandazi* – a sweet fried pastry.

[126] The *Tanga AIDS Working Group* (TAWG) is a non-governmental organization in Tanga city, launched by Dr. Firimina Mberesero and Dr. Chaze in 1992 and was officially registered in 1994. TAWG dedicates itself to the care and support of PLWHA. Information is retrieved from an expert interview with Dr. Firimina Mberesero conducted by the PI (08.08.2008).

negative reactions, with her husband as well as her friend among the first to know. She also experienced involuntary disclosure to friends and neighbors.

7.2.2 Neema

When Neema[127] entered the interview room she seemed self-confident.
Her light skinned face was framed by an Afro-wig[128] and she wore a white-brownish batik dress with a piece of the dress' fabric tied around her head. Two wooden bracelets were clanking around her wrist and a golden signet ring was around her left middle finger.

She placed her black-golden handbag next to her on the floor as she sat down and a crunched brownish envelope on top of her feet, on which she is wearing black sandals. Her appearance led me to believe that she was financially secure.

She is forty-two years old, born in Tanga city and now lives in Makorora, a remote area of the town. She belongs to the *Digo* ethnic group, and is Muslim.
Neema was once married - having one daughter who is HIV-seropositive - and is a widow.

She went to primary school until seventh grade and today works as a typist and earns her own money. Her household, consisting of four people, has an average monthly income of 120 000 TZS.

She was brought to PASADA[129] by her brother and his wife because she was suffering from painful shingles (Herpes Zoster). A blood sample was taken from her and she said: "They did not inform me that I would be tested for HIV…" (Neema, Section 4). When she received the result, her reaction was as follows:

> *"…I cried. When I stopped, my brother asked me: 'Why did you cry?' I answered that I think I am going to die. He told me: 'No, having the HI-Virus does not mean that you will die. Your life will be normal like others…'"* (Neema, Section 4).

She then partially told her family and friends and mentioned that her status was involuntarily disclosed to her colleagues and some neighbors.

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[127] Interviewee 06.

[128] At the time of research it was popular to wear a wig among middle-aged women, which was highly fashionable and a sign for being well off financially.

[129] The *Pastoral Activities and Services for People with AIDS in Dar es Salaam Archdiocese* (PASADA) is an organization operated by the *Roman Catholic Archdiocese* in Tanzania. It is offering care and help for poor urban people in Dar es Salaam being infected by HIV and tuberculosis. For further information please visit the following website of USAID (2009): http://transition.usaid.gov/stories/tanzania/pc_tz_firstlady.html [08.05.2013].

Since her diagnosis she has been taking ARVs and according to her has never missed a dosage. She also indicated that she never went to a traditional or spiritual healer[130] during her illness.

During the whole interview she listened attentively and seemed to feel very comfortable, confiding in us: she gesticulates, claps her hands in astonishment and laughs and cries every once in a while, answering the questions asked after serious contemplation.

7.2.3 Amina

At the time of her interview, Amina[131] was a 63 year-old woman. She was born in Tanga city and lives in Msambweni, a village close to the city. She belongs to the ethnic group of the *Bondei*[132], and is Muslim. She went to primary school until fourth grade and earns her money selling charcoal and coconuts. She shares her household with another person, together having about 30 000 TZS for monthly disposal. During her marriage she gave birth to two children, although she is now divorced from her husband, who has since married another two wives. She cared for her son, who now deceased, throughout his illness with AIDS and assumes that she became infected during his care. Her younger brother died of HIV, too.

Her son encouraged her to get tested, as she had a constant fever. After receiving her diagnosis in 2006 she started disclosing to every family member possible, as well as friends and colleagues, though chose not to tell the neighbors.

Amina wore a pink dress, covered by a black Buibui and on top additionally covered by a Khanga around her waist and her head. On her feed she wore brown sandals. Her handbag rested on her lap during the interview. For jewelry she wore earrings and a golden signet ring on her left middle finger. Her eyes were darkened with black coal.

Following her HIV-test, Amina started to take ARVs. At the time of the interview she had only missed one dosage and she had never visited a traditional or spiritual healer since she is suffering from chronic sickness.

During the interview she listened carefully, leaned forward and backwards, emphasized her statements with energetic and sweeping movements, clapped on

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[130] While referring to a traditional or spiritual healer in this context I am most aware of the strong simplification of the professions implicated by the terms used. With these extraordinarily wide categories I do not want to set a "homogenous social reality" (Kleinman 1995:23), but rather want to evoke the myriad of endless variations and professions. As the work is not dealing with healers specifically the terms in Kiswahili distinguishing between traditional and spiritual healer were used during the conduction ensuring distinctiveness.

[131] Interviewee 11.

[132] The *Bondei* ethnic group is mainly located at Muheza, a city in Tanga Region.

the table from time to time. While listening to the questions she pulled the Khanga behind her ears, using it to dry her sweating face.

7.2.4 Rose

Rose[133] looked fragile and aged when she entered the interview room. In her hands she carried a blue plastic bag and a small and slender handbag out of which her blue patient card poked.

A Kitenge[134] lay loosely at top of her head. A blue headscarf framed her face, knitted at the back of her neck. On top she wore a blue blouse with a white lace and a skirt made from Kitenge and green sandals. At the beginning of the interview, listening to the instructions, she propped her head on her elbows.

Soon we earned her trust and she was very emotional while talking. She laughed, had tears in her eyes from time to time, whispered, shouted and gesticulated.

Rose came to test as she was suffering from ongoing sickness. When she received the result she was very confused because she had not had sexual intercourse for a long time.

She is a 50 year-old divorced woman. At the time of the interview she lived in Tanga city, practiced Islam and belonged to the ethnic group of the *Bondei.*

She attended school until seventh grade and now earns her money selling soap.

Her household contained 13 people in three rooms, living off of an income of 100,000 TZS per month. Although she was pregnant once she lost her child. Many of her family members were already dead and she revealed her HIV-positive result to every living relative, as well as some friends and colleagues.

For a month and a half she has been taking ARVs regularly and has only missed one dosage. She states that during her ongoing illness she never went to a healer in order to seek help.

7.2.5 Elisa

Elisa[135] is a 30 year-old woman, Roman Catholic and belongs to the *Pogoro*[136] ethnic group. She was born in Tanga city, and now lives together with her boyfriend at Mikanjuni[137]. Her only child died at the age of two.

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[133] Interviewee 14.

[134] A Kitenge is a long piece of fabric, which is chosen according to its design and color. Kitenge are more expensive than Khanga and are normally used in order to sew a skirt and a top or even a complete dress out of it and not worn loosely, except for left over pieces as scarfs for the hair. As with Khangas, qualities differ as prices do.

[135] Interviewee 27.

She was raised by the paternal side of her family from the age of three, having a stepmother who, according to Elisa, does not love her (Section 90).

She wore an apparently brand-new oversized grey T-shirt decorated with the lettering *Kentucky* and a skirt and sandals when she entered the room. Her hair was loosely covered by a light pink scarf with a white crocheted lace at the margin, the end of which lay on her shoulder. In her hand she carried a mobile phone as well as a small brownish paper envelope as a moneybag and her blue patient card.

Elisa seemed to be very open, self-confident, smart and talkative.

During the interview her mobile phone suddenly rang and she had to disrupt the interview session after the questionnaire to fetch the milk, which she had to boil to ready it for sale.

Later on she returned to continue the interview after receiving the milk, carrying two big plastic buckets, placing one of them on the corner of the table next to her. Additionally she carried a thin plastic bag stored in another plastic bag used as a moneybag containing a total of 5500 TZS in bills and some coins.

On her way back she must have forgotten her headscarf, as her hair was no longer covered.

Elisa tested positive for HIV in 2005, when her father forced her to get tested.

Initially she did not disclose the result, as she was too afraid of her family's reaction, in particular that of her stepmother and therefore pretended to be healthy.

As she was still suffering due to sickness her father did not believe her claim that she was negative and forced her to be tested again. That is when the nurse of the VCT asked him:

> *"…what have you come for with your daughter? I have already tested your daughter and given the results. Why are you coming with her again? 'I came with her because my daughter did not give me the correct results and I find her condition not good. Maybe you have given the wrong results?' (her father answered). She (the nurse) said: 'I am asking you and your daughter to go home. If she says she has a headache give her Paracetamol, if she says maybe back pain just give her Paracetamol because she doesn't want [to disclose]!' I saw that she (the nurse) has already done what? Showed him the way (i.e. disclosed to him). I said okay, I started to cry loudly right there. I cried and I told him it is true, I am infected – but the problem with my father – I know if I tell him he will tell his wife and his wife had already started to stigmatize (i.e. discriminate) me even before I got the results. So if she receives results like this one how will I live with her there at home? I will live with her while I am not comfortable ..."* (Elisa, Section 30-31).

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[136] The *Pogoro* are located around Morogoro, a city of the Morogoro Region, located in the mid-east of Tanzania.

[137] Mikanjuni is an outer area of Tanga city.

After the result it took her about two weeks before she told some other family members and friends, although she was truly afraid of her stepmother's reaction – and her doubts were reasonable as her stepmother had already spread the message of her positive status to neighbors before she even had been tested.
Elisa visited primary school until seventh grade, now earns money selling scones and milk, and has a personal budget of 40 000 TZS per month for her own.

Before she got tested and after her diagnosis she additionally consulted a traditional healer as well as a spiritual healer, but never took traditional medicine, although she is a member of TAWG. Since being tested she has been taking ARVs and stated that she has missed a few doses.

During the whole interview she was very eager to let us take part in her life and daily struggle, and was very open and talkative.

7.2.6 Halima

Halima[138] appeared as an energetic woman when we first met her, presenting herself very self-confidently, speaking in a loud voice, and with arrogant undertones. She entered the room in a black Buibui with a black veil covering her face, only showing her eyes, talked of in Tanga as the *Ninja style*[139]. After just a few steps into the interview room she unveiled her face.

Underneath the Buibui she was wearing a green and white dress with long sleeves. Her head and shoulders were tightly wrapped by a Khanga. She did not wear any jewelry and her fingernails showed rests of Henna color.

She placed her handbag and a blue scarf on the floor next to her. On her feet she was wearing black sandals.

At the time we conducted the interview with her she was 38 years old and widowed with three children. In order to marry her ex-husband she had to convert from Christianity to Islam, being penalized by her family, who according to Halima "hate" her (Section 126). For example she mentioned that she once had a serious accident where she had lost consciousness for three weeks. Her family

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[138] Interviewee 56.

[139] The term *Ninja style* refers to the clothing style of Muslim women in Tanga wearing a Buibui and additionally a *Niqab*, a black veil covering the face except the eyes. Sometimes an additional lighter veil is used on top to cover the face including the eyes.
Female patients not wearing this style often complained about women at the VCT wearing the Ninja style, giving them the chance to be totally anonymous, not disclosing to others involuntarily by hiding their body, which they thought to be unfair.
I could observe that patients visiting the VCT often unveiled their Niqab after leaving the hospital compound and in personal conversations I was told that young women preferred to wear the Ninja style while dating, not being able to be discovered by relatives, neighbors or friends - the Ninja style therefore fulfilled the effect of staying anonymous.

turned their backs on her and did not provide any support. Therefore Halima very much depends on herself.

Her divorced husband had fallen sick and died in 1989, she attributes his early death to his womanizing lifestyle (Section 9).

Halima lives at Usagara[140], located close to Lake Victoria in Mwanza Region. Being from Moshi at Kilimanjaro Region, she is a *Mchaga*[141], who are known in Tanzania for their business savvy. She went to school until fourth grade of secondary school and then dropped out. She now earns her money selling gemstones from the mines. She estimated her monthly income to be about three to four million TZS.

Halima saw a play dealing with people infected by HIV, who suddenly died and left their children behind. As her husband was very sick before he died, she then decided to get tested in 2003.

> *"…before testing ... there was a (theatre) show there at Usagara school now when they did it they were playing those shows and those shows were very very sad. (They were about) how a parent until he/she dies, everything the children are crying and the father started (to die). (…) All of a sudden the mother is going to be buried and the children faint. Things like these that made me very sad and I thought ... it is better and I also go and test before this condition reaches me (...) Because my condition, these children don't have a father already. I am the only one remaining so I said and me I come and become like this (like the show) with whom am I am going to leave my children with? In which condition am I am going to leave them? So that is when I thought it is better I go and test. ... But from the beginning I knew already that I am infected because my husband had Herpes Zoster in 1989 but in 1989 it was not very clear that Herpes Zoster is one of the AIDS symptoms but then I knew and after knowing that my husband had Herpes Zoster and after that I had three children with him (pointing with three fingers to emphasize) it means even me I have this problem so I was just observing and observing. But after I saw some shows I went to test there at the thirteenths (i.e. the VCT from TAWG at thirteenth street)"* (Halima, Section 2-8).

She then became a member of TAWG, first receiving herbal medicine before she started with ARVs. She advised she had never consulted with a traditional or spiritual healer due to her illness. She disclosed partially to her family and friends, as well as to her lastborn child, suspecting the child to be positive, too, although the children have not been tested so far.

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[140] Usagara is located at Misungwi District in Mwanza region, at the shores of Lake Victoria in the north-eastern part of Tanzania.

[141] The *Chaga* ethnic group is originally located around Arusha and Moshi near Mount Kilimanjaro, at the Arusha Region and the Kilimanjaro Region in the northern part of Tanzania.

Halima reports to adhere to the ARVs except for the time she was hospitalized and comatose.

At the beginning of the interview she seemed impatient, asking how long the interview would last. After some time she seemed to forget her initial hurry, answering very openly, obviously enthralled by the questions asked.

7.3 Interview results – qualitative data

Results are presented, depending on the codes and relevant sub-codes. They are ordered thematically, as well as listed according to each interviewee. First, results concerning the topic of *disease* and *illness will be presented,* including a third category, referring to the term *normal.* No clear codes could be set concerning *stigmatization* itself. As codes could be clearly set concerning *discrimination* and *self-stigmatization,* results will be presented here, while *stigmatization* will be embedded in the results concerning *discrimination.* Before presenting the results it needs to be mentioned that results overlap from time to time, and were even consciously listed twice, as codes were intertwined and only understandable in context. Furthermore, citations have been slightly modified in order to ensure fluent reading where appropriate as described in Chapter 7.2.

7.3.1 "Don't wait until you are carried in a plastic bag"[142] – Interview results in the context of disease

The term *disease* turned out to be a very central term in the interviews. While some women talked about their experience concerning disease in detail, others only mentioned it in passing.

Mariamu only talked about disease in the context of her test results and mentioned that she trusts the doctors and decided to believe the positive result immediately (Section 20). She took the test together with her friend who was told her results likewise. Mariamu hereby refers to the day "she was told the truth" (Section 76).

In contrast Neema talked about disease more extensively. When her relatives brought her to PASADA she suffered from reoccurring Herpes Zoster in March 1998. She herself was not aware of HIV at that time (Section 4) and her test results were presented to her only on paper and not explained. When she received the result she felt the following: "I was so confused. I lost hope and felt that was the end of my life and everything. I cried a lot" (Section 4). Upon receiving the

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[142] Citation from Halima, Interviewee 56, Section 148.

positive result she was terrified of dying (Section 50), as her husband had already died of HIV (Section 18). She was then told that she would not die but had to protect herself from "opportunistic infections and other diseases" (Section 4).

She was given herbal medicine, as ARVs were not available at the time of her testing, but started to become increasingly sick. "I could not eat during nights. I did not realize that my CD4 was low" (Section 8).

As her CD4 lowered she went to Muheza, a city in Tanga Region, where she was started on ART. Unfortunately, she suffered from many side effects such as vomiting, high blood pressure and massive weight gain (Section 10). Although she complained and said "my body is allergic to these drugs" (Section 10) she had to consult many doctors in different hospitals before her regiment was changed accordingly and she was advised on how to take the ARVs correctly (Section 10, 12). According to Neema "many abdominal organs were not in a good condition" while her "liver and spleen had enlarged" (Section 12).

Neema sometimes cannot believe her destiny and says: "Imagine, from 1998 until now. You can't believe (that I am still alive). And there are others back to the 90s they survive with HIV and AIDS" (Section 130).

She did not want to tell her daughter and nor did she want her to get tested. But as soon as her daughter developed Herpes Zoster she started worrying.

> *"I even refused the doctor's advice to test my daughter. That time she was in nursery school. I told him: 'Do not test her.' Because I saw her and she looked healthy. Although they didn't tell me when she tested they kept it a secret. They let me know when she found having shingles (Herpes Zoster). When she had this disease I started worrying. I did not sleep the whole night. I asked myself, why is she suffering from this disease? I brought her to the hospital but she told her aunt about this. They continued to hide it from me but later on they told me. I felt pains inside my heart but I had nothing to do about it, just to accept (it) as it is"* (Section 50).

Amina on the contrary had ongoing fever and went to the tuberculosis department to be examined (Section 94). When she tested for HIV she too believed the result immediately upon receiving it and did not feel the need to confirm the result by testing elsewhere (Section 28). Concerning her status people were sad when she told them: "When you get this disease people then know that the journey has arrived" (Section 66) and "people say that HIV and AIDS kills, is it not true?" (Section 70).

Amina copes with the result by the following:

> *"I was just proceeding as normal. Having no problem, except these minor problems, (they) are normal to a human being. But I had no other problem and I have accepted that disease and it is a normal disease. It is happening right now, there is no way of going against it" (Section 10).*

When receiving the results it was explained that she could have become infected not only through sexual intercourse but through nursing and attending to sick persons too (Section 32).

Rose felt sick when she went to check her health status at a dispensary. As she had to pay for the service without receiving any results, she decided to test for HIV free of charge at the *Kikwete campaign* and was then referred to the BRH. She asked a friend to accompany her, and her friend answered "'Aren't you scared?' I told her: 'No, I can't be scared, because anytime I can become sicker and I can also be discovered (to be positive)'" (Section 74).

They started with ART immediately and her response to the nurse when asked whether she wanted to take ARVs was: "'If you have seen that I have a problem you must prescribe some drugs for me. Can you leave me just like that?'" (Section 8).

She follows the advice given by the doctors to the letter as she does not want to put herself at risk and therefore she is careful to carry her hospital card wherever she goes to and does not take any drugs except for the ARVs (Section 94).

Concerning her test results Rose "… was in deep thoughts. Being infected with this disease you must have sexual intercourse (she thought). Now I had no sexual intercourse with any man (…) so how did I contract the disease?" (Section 114).

Although she was deeply frightened by the result she says in context of the disease "… maybe I will die because if it is to die even if I had walked out of this building very likely I can be knocked by a car and die, I can get fever all of a sudden and die, even Malaria kills, doesn't it?" (Section 18).

Concerning her mode of infection Rose can only speculate. At the beginning she had Herpes Zoster and received blood transfusions, which may have infected her. On the other hand she received very expensive and strong tablets to treat her leg problems and she could not eat or drink during that time which, according to her, may have led to her infection as well (Section 30).

For Rose having the disease was "created by God" (Section 28) and her being positive is

> *"…normal. It's just a disease like getting fever. That is the way they viewed it because you cannot escape from an accident God has written. When you leave here and I am out of that gate I am not expecting to be knocked by a car, no! But I can get out and be knocked by a car and die. Will you then tell me that I have done it purposely so as to be knocked? Is there anyone who wants to die? No. So that is the way it is"* (Section 88).

Elisa was suffering from ongoing fever when she decided to get tested for HIV in 2004. At that time no medications were available (Section 20). She asked herself

> *"What is the problem that is disturbing me? If it is the HIV-infection I should know. If I don't have (the infection) I know (…). If it is to die, fine, the Lord God can just take me. If not, I am not ready, the Lord God can guide me and I will live"* (Section 20).

When her blood was drawn the nurse inquired how she would react and feel in either case and she answered

> *"I told them I will thank the Lord. I will thank God very much if I will be negative. I will thank the Lord God and I will be able to protect myself more, if it is just God's problems. If it is the (problem) of the world here (i.e. witchcraft), if a human being decided to bewitch me, I will increase to do what? To treat myself. If it is from God, then that is it. 'And if you are positive?' I said I will continue to thank God for the particular problem he has given me because I was not such a person practicing prostitution. I mean, every time I am with a new man it is just God's power. If God has arranged you will die out of this problem, then you will die out of it. If it is not your time, fine"* (Section 27).

Before Elisa took the HIV test she went to a traditional healer to seek help. There, the healer told her that her grandmother had bewitched her. Ever since receiving her HIV-positive test results she has been very skeptical of traditional healers and says that they by default *presume* bewitchment (Section 142). Now Elisa considers "…traditional healers [to be] (are) liars…" (Section 144), as only "one out of ten" (Section 144), would either advise a person to go for an HIV-test and then return or who has done divine reading and truthfully tell the person seeking help that he or she is HIV-seropositive (Section 144).

Concerning the ARVs Elisa is thankful to God as they are improving her CD4 count which has been rising since she started ART in 2005 (Section 152) and presents herself compliant arguing: „I am making a follow up to swallow the drugs so that all the infectious diseases disappear and do not to attack me again. That is why I try my level best to swallow the drugs" (Section 154).

Halima talked about disease at length. As she already suspected she was HIV-seropositive before she tested she told us that she felt normal when she received the results in 1993 (Section 20). "This is a normal disease and God has planned all the diseases for you, so you don't have any other means of (accepting it)" (Section 26).

According to her she is only aware of her infection when she collects her medication at the CTC and as soon as she arrives home she feels healthy again (Section 28).

Halima states that she was infected through sexual intercourse, from which she now abstains, arguing, "[t]his situation of having sexual intercourse with a man leads to loss of energy. So I do not see the need of that" (Section 40).

Concerning HIV Halima says

> *"I feel normal because this problem now is not a one mans problem it is (a problem) for everyone and if out of ten people maybe all of them are infected or only one is not infected now this (HIV) is an issue for many people and not only one person anymore" (Section 106).*

Halima also advises people to get tested and says, "[d]on't wait until you are carried in a plastic bag" (Section 148). When she once did so with a neighbor the woman accused her of falsely suspecting her of being positive, while the woman soon died of tuberculosis (Section 148-150).

Concerning her medication Halima is thankful and prays to God (Section 154, 160) telling us "I know that we will use these pills and then one day God will discover the medication. One day medication will be found and (they) will help us and the problem will be finished completely" (Section 160).

7.3.2 "I was deadly alive"[143] – Interview results in the context of illness

At the time of testing Mariamu suffered from everyday sickness. She reported that she was suffering from fever and heavy ongoing headaches (Section 54). That was the time when she decided to get tested as she heard people saying that when should you have ongoing sickness you should get tested. When she talks about the HIV-test she refers to "get her health-status checked", which she experienced as a normal situation (Section 52) and she emphasizes that she was not afraid (Section 32). To her the reason for her illness could lay anywhere.

> *"…you don't know. It is a thing (i.e. HIV), which can also happen to you. And what will it be? Maybe it is fever everyday, but there are other hidden things behind it and you don't know what the things will do to you or (what) will happen to you"* (Section 52).

When we further asked about her decision of disclosing her status to all her close relatives, she answers "…nobody can hide illness. The one who hides illness is mad, right?" (Section 207).

Neema did not talk much about her personal illness experience. Concerning her positive status she experienced that "[s]ome of the people can't believe it (i.e. her being positive) and they come to ask me … and it will be foolish to say 'No!' (i.e. I am not positive), because I became critically sick for a long time. I was deadly alive" (Section 130).

According to Neema "…unfortunately some people become sick while hidden inside their house. When you visit (them) their relative tells you 'He/she is sleeping!'" (Section 130). Concerning her own positive status and the habit of

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[143] Cited from Neema, Interviewee 06, Section 130.

Swahili people in hiding sick family members she explicitly asked her family not to disturb her when she is sleeping and a visitor comes - but should she be awake she gladly welcomes them (Section 130).

Amina also only rarely talked about her illness during the interview. She only mentioned that her condition was not good and she was seriously sick. Initially, she did not reveal to her mother her HIV-seropositive status, arguing that her mother is older than herself (Section 66) and told her "I am just sick mom, *in a normal way*" (Section 66; emphasis added, L.B.); that is until later on, when she herself gained strength and felt well again.

Rose on the other hand described her illness in detail. She first experienced leg and hip pain at home and sought treatment at a health center, where nothing could be found wrong with her. The very next day she passed Tangamano[144] and heard people were testing for HIV free of charge (at the Kikwete campaign). She then decided to get tested for free instead of paying money at a health center (Section 4). She snuck into the tent without anybody seeing her (Section 8) and learned that at the time of testing she was seriously sick (Section 14).

When asked about the situation before testing she answered

> *"…as a human being you must be terrified when you are ill because you do not understand what you are suffering from or you can not know what will be the outcome. So you will be a bit terrified as I don't know this and that. So that was the terrifying situation I was in and it was not more than that"* (Section 18).

When she left the tent she was given a referral form for BRH and that is where she was confirmed positive for the first time and immediately prescribed drugs (Section 20, 24).

Rose is still suffering from severe pain in her legs and teeth pain being very thankful to receive ARVs (Section 40-42). Sometimes she feels too sick and needs rest from her activities, although she states that food gives her energy (Section 118).

As she was suffering from severe sickness she told certain people of her problems in case she ever needed their help. As she is childless she also told one of her male relatives so that he could take care of her burial in the case she may die (Section 94).

Rose completely trusts the doctors concerning her sickness and health status, as they are the ones helping and treating her (Section 218). Concerning the ARVs Rose doesn't complain of any side effects except "…only sometimes I feel the

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[144] Tangamano is a place located in Tanga city, offering space for holding a weekly market and serving as a center for social gatherings.

knees want to hang. Now I asked the doctor and she told me it is because of the drugs" (Section 162).

Elisa felt very sick and was suffering from fever when she decided to get tested for HIV. She had developed multiple "boils" (presumably swollen lymph nodes) on her head, under her armpits as well as her genitals, which caused her to suffer (Section 4).

Elisa tells us

> *"…I said, let me just go and get tested so I know what the problem is, which is disturbing me. If it is the HI-Virus infection I should know, if I don't have (the infection) I know so that I can put myself if it is to die, fine, the Lord God can just take me. If not, I am not ready, the Lord God can guide me and I will live. So I was waiting to get into the nursing room to take (the test), to go for voluntary counseling"* (Section 20).

When she received the results she reports, "I was in sorrow. I started feeling I am losing energy, feeling pains, not happy. I know that I am already in a life which is not good" (Section 2).

In contrast to all other women interviewed Halima emphasized that she was certain of her infection before she decided to go for the test. Her husband had suffered from Herpes Zoster in 1989 and afterwards she had three children with him. At that time she was not aware that Herpes Zoster is a disease, which often affects people infected with HIV. After she saw several plays on this topic she decided to get tested as her main concern was the care of her children in case of her death (Section 6-8).

7.3.3 "It is normal. It's just a disease like getting fever"[145] – Interview results concerning the appearance of the term normal

As the expression of the term *normal*[146] noticeably often appeared in the context of disease and their lives with the disease in every interview analyzed and as already seen from the results presented above, I would like to provide a brief résumé of results in this chapter in regards to the term *normal*. During the interviews presented in this book the word *normal* appeared exactly fifty times whereas Amina alone used it for twenty times and Mariamu (Section 181, 220), Amina (Section 8, 10) and Halima (Section 26) have used the word *normal* in the direct context of *disease*.

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[145] Stated by Rose, Interviewee 14, Section 88.

[146] Here it is referred to the Kiswahili term *kawaida*.

Mariamu discovered “lots of people” (Section 220) at the CTC who were infected, which made her *feel normal* and *taking the disease as normal*. On the contrary Neema felt devastated when she received the results and her brother kept telling her “[h]aving the HI-Virus does not mean that you will die. Your *life will be normal* like others” (Section 4, emphasis added, L.B.).

After having received the result Amina says that she will “…be *living normal*. There are some of the things which I can restrict myself to but, *I am just normal*” (Section 50). For her “being HIV-positive (…) is a *normal thing*. Lots of people are infected. To me these are like *normal things* for nowadays” (Section 8).

For Rose and Halima *having the disease is normal* too as it was created and given by God (Rose, Section 28; Halima Section 26), while Halima adds “HIV is *a normal disease*” (Section 26).

7.3.4 “The expected deceased – that is what they were calling me”[147] – Interview results in the context of discrimination and stigmatization

Strikingly during the interviews every woman reported knowing of or experiencing discrimination directly.

In the context of discrimination women reported on different situations of being talked about. Rose reports that

> *“[w]hen other people know that one is infected especially in the street they will gossip, isn’t it? When you just pass (they say) ‘She is an HIV/AIDS victim!’ When you pass people they don’t know if it is something which happened accidentally, people don’t know even how I contracted the disease. People will think that I have committed adultery while that is not the way it is. So I didn’t like that thing of being an advert”* (Section 98).

Neema said that people gossiped cruelly (Section 70), and Halima also comments „…people were talking bad about me a lot. Everywhere I pass people talk and stop“ (Section 96), and look at her. When the interviewer asked how she reacted she answers, “I did not do anything. I just thanked God. Now what are you going to do?” (Section 100).

Also Amina said that people whisper and gossip about her (Section 104) and Elisa tells us that her stepmother, among others, spread the word of her infection even before she tested (Section 27).

The interviewees reported the spread of rumors regarding them. Mariamu suspects her husband’s family of spreading many rumors about her (Section 234) and she says when asked about her neighborhood: “How I feel in the streets (at our living area)? We threaten each other (with rumors)” (Section 378). Halima is

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[147] Statement made by Elisa, Interviewee 27, Section 114.

worried of rumors, especially when people talk about her potential death and advise her: "'You better take care of your children! Look, in two days she will die!'" (Section 64).

Elisa also witnessed these rumors after her stepmother's gossip. They were telling her "'…we count two months (until she is dead). I don't know if she will still be alive! Or one month! I don't know if she will finish it! That is the expected deceased!' Expected deceased - that is how they were calling me" (Section 114).

During ceremonies[148] Mariamu is particularly afraid of segregation as experienced by a fellow friend, because according to her "[t]o be discriminated is the only thing that worries me" (Section 104) and she adds "[t]hey might also do the same thing to me, because between ourselves, we are relatives, we do, we segregate each other" (Section 106, 108). Elisa reports that if anybody knows that you are positive they tend to say

> *"'That one has got HIV that way, that way!' if they see you in a ceremony. They wont even invite you in ceremonies. They know when you go there maybe you might infect them by using their utensils"* (Section 74).

Elisa experiences segregation from her stepmother. Her father already knew that his wife would segregate her daughter and said that he will even buy a cooker for her, so that she can cook and eat alone (Section 30-31). And Elisa reports about her stepmother:

> *"Especially food she did not want that we eat together, saying I can infect her she says at times. When she leaves the kitchen for me and I cook, she is horror-stricken. But I just eat the food, what will I do, but I don't want to"* (Section 62).

However, when she told to the people close to her of her disease she received both negative and positive responses. Some of them encouraged her and assured that they would not discriminate her. "'Do you think we will stigmatize (i.e. discriminate) you?' I thought, I don't know! (And they answered) 'Don't harbor such thoughts. Just see us like you and we see you like us'" (Section 110).

Halima has observed the segregation of her aunt, who was also infected, which made her worry.

> *"She was given her own plate, her own cup, everything of her own, even when she just touches a cloth then nobody wants to touch it again. So on the day my aunt died all the dishes where cleaned thoroughly. They were washed and not used for three days now this is an act which a family had and this means, it doesn't mean that now they wont stigmatize (i.e. discriminate) me"* (Section 62).

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[148] When writing about ceremonies in general it is referred to any festivities, such as birthday parties, weddings or even burials.

Later she modified her statement as she had not experienced segregation herself and justified it saying: “Now everybody in this world of today, every one has doubts if he or she is infected or not” (Section 104).

Elisa often confronted accusations and assumptions. On the one hand she reported she worried that people might assume she had engaged in prostitution (Section 86) and feared people predicting her early death (Section 114). Additionally her stepmother already assumed she was positive before she even took the test. She also described the situations of other people with HIV. As soon as they were seen at the CTC people often assumed that they were positive (Section 74), while Neema had the opposite experience. People thought she would fabricate a positive result in order to receive monetary support (Section 80).

Elisa mentioned that she felt people were waiting for something to go wrong for her so they could maliciously laugh at her (Section 96). In particular she fears that neighbors might laugh at her (Section 104) and she adds: “It is better when your relatives laugh about you than your neighbor, you understand me?” (Section 98).

Neema, Mariamu (Section 234) and Elisa (Section 100) also experienced taunting in public as people would point fingers at them. For Neema this reaction was difficult for her to comprehend with and Elisa experienced finger pointing at the hands of friends and neighbors and says that a “[b]ig percentage of people were pointing fingers on me because my health was not good” (Section 114), although now and after support of TAWG she says “[e]ven if someone points a finger on me I don’t care. What I want is my health to be good” (Section 100).

Elisa describes her fear of discrimination saying, “…a big percentage will love you when you are well, but when you are sick a big percent of people don’t like (you)” (Section 86).

Another form of discrimination Rose, Elisa and Halima experienced was the accusation of prostitution. Elisa heard people saying “‘…it is due to her (committing) prostitution, let her die, it is due to her prostitution, let her die!’” (Section 86). Halima articulates her experiences as follows:

> *“Most of the time people take it as someone was a prostitute, or she got it when she was selling herself. So the whole society is looking at you like you were not a good person and you became a very bad person, because to get such a problem and there are so many married people who get this problem because ... you cannot tell your husband to use a condom. ... Your husband has been married to you for the past twenty years and today you come and tell him: ‘Today use a condom!’ How can you tell him? So you won’t know if he brought it today or since yesterday or the day before yesterday! It is like this, that you have to be able to cope with such a situation and that’s why you find out, that most of the married women are the ones who are infected”* (Section 112-114).

7.3.5 "If you do not wear gloves, do not attend me"[149] – Interview results in the context of self-stigmatization

Aspects concerning self-stigmatization or behavior, which could indicate possible self-stigmatization, were only randomly found and indirectly addressed. Nevertheless women often reported hiding medication in order not to disclose involuntarily to others. Mariamu received ARVs she was supposed upon labor during her pregnancy. She tells us that she was hiding the medication until the labor pain started and then told her husband about it (Section 44). According to Mariamu, the people see her "…*as an HIV-infected person.* I talk with them, laugh with them, but they do not stigmatize (i.e. discriminate) me. I am thankful for that" (Section 238, emphasis added, L.B.).

Neema mentioned self-stigmatization only once and rather described stigmatization while talking of others. She indicated that Swahilis[150] have the habit of hiding sick people in their houses, which automatically leads to the isolation of the sick (Section 134-136, 130-132). And she adds that people in general hide a positive diagnosis. She does not want to tell neighbors that she is infected due to fear of discrimination, but then meets them at the CTC and learns that they too hide their status (Section 54).

Neema did not want her daughter to get tested for HIV and did not tell her daughter that she was positive and argued the following:

> *"I did not have deep knowledge about HIV. I thought I wouldn't survive. I was really confused. I believed that I would loose my stability when I found me and my daughter both having HIV, if it would happen that I will die"* (Section 50).

When we asked her concerning the disclosure to her mother she said

> *"(I felt) bad but later I disclosed to her so that she can understand on how to take precautions while attending me. Like a few months ago I became ill. I told her to wear gloves, but she refused. I told her, if you do not wear gloves, do not attend me. I got relieve, I asked her what if you go for the HIV test. 'Why?' (my mother asked me). I told her, you took care of me for the long. She said that 'Why do you think that (of me being positive)?' I told her that 'You have attended me for a long time. You never know what happened during your assistance. In addition you are coughing.' Now she has chest problems. She agreed and went for the test and she was found (positive). So by now she is just there she is matured enough but she understands" (Section 62).*

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[149] Citation from Neema, Interviewee 06, Section 62.

[150] When referring to the Kiswahili term *Swahilis,* people refer to Tanzanians living in the coastal region of Tanzania.

Amina briefly recounted her pill taking. She hides her pills while taking them. In case somebody asks her concerning her pills she pretends to take medication against Malaria but she does not want to tell anybody of her taking ARVs (Section 146-148, Section 150).

Concerning HIV in families she states twice that "HIV and AIDS is a secret" (Section 54).

Rose also hides her pill taking and does not store the pills in pillboxes decorated with a red ribbon, because otherwise people would know what medication she takes.

Concerning her HIV-seropositive status she says " I feel like, I don't feel, I feel good, but sometimes, I just feel shy, that people might think that I have done bad things. That is why I got it. Maybe I practiced prostitution…" (Section 136).

Elisa speaks about her testing experience and admission at TAWG:

> *"Especially after we had been taken for a seminar, there was a certain seminar for people living with the HI-Virus, it is when I got at least a certain elaboration but if it was not the seminar I wouldn't have known anything because there is a difference to hear it from someone and attending a class. It is better to get into the class and be explained - then is when you understand what is going on. That was at the beginning, sometimes I remained inside (the house). I felt trouble to get outside. I was hiding, eating was a problem. I saw it is better to just die. But I am so thankful. When I attended the seminar it has removed my fear. I found my fellows of different status, I said, really disclosing helps to reduce the fear and someone can live"* (Section 60).

In the context of ceremonies Elisa adds that she might not even be invited as "they know when you go there, maybe you might infect them by using their utensils..." (Section 74), guessing at the opinion of the other ceremony participants.

Halima openly talked about stigmatization and discrimination at the hands of others. She suffers from self-stigmatization and describes a situation where she asked a relative for help and money to buy food and was rejected because of her positive status. "So things like these make you doubt ... it means she has affected you already in your brain which means you got this problem (of HIV) while prostituting" (Section 236).

She adds

> *"... most of the time the people take it as someone was a prostitute, or she got it when she was selling herself so the whole society is looking at you like you were not a good person and you become a very bad person"* (Section 112).

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8. Interpretation of the Results

In the following chapter the results concerning (self-)stigmatization and discrimination in the context of illness and disease, referring to HIV and AIDS , and how they play an important role in the lives of HIV-infected women in Tanga Region will be discussed.[151]

8.1 Interpretation of results concerning illness and disease

As presented and discussed in Chapter 4.2.3, less than 50 percent of the overall Tanzanian population have basic biomedical knowledge of HIV (The United Republic of Tanzania 2010:23). When talking about the disease the fact above is confirmed: most of the women interviewed and presented here reported to know little about the biomedical facts concerning HIV or the different modes of infection at the time of testing. For instance, for Amina and Rose sexual intercourse was the only mode of infection (Chapter 7.3.1). This could be a possible sign of the influential transfer of knowledge by (inter)national organizations with a biomedical focus, as heterosexual intercourse was and still is promoted as the most common way of infection in sub-Saharan Africa. Interestingly nearly all women interviewed were shocked to receive their results, being aware of the possible consequences and outcome accompanying an HIV diagnosis.

The confidential use of biomedical (technical) terms by the women interviewed was noticeable, especially bearing in mind the limited years of school attendance or no school education at all. Biomedical terms of diseases, diagnostic tools such as the CD4 count, and the importance of compliance to ART were mentioned. This might show the strong impact of biomedicine and in addition the hospital setting on the women affected. However, this result must be discussed in the context of defence mechanisms (intelectualization) as referring to western psychological theories of dealing in this case with conflicts resulting from a disease and illness (Hoffmann et al. 2004). This is of particular interest since common beliefs concerning HIV and AIDS may change to deal with the disease on a biomedical level after diagnosis. Another aspect is that a biomedical model may diminish the guilt that accompanies the disease. Furthermore the sample may be biased since a biomedical concept of the disease is needed for an establishment of effective therapy and women with a biomedical concept of their disease may be overrepresented. Accordingly it is suggested that medical professionals may

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[151] Again it needs to be put into consideration that we might deal with a convenience sample and therefore results and interpretation conducted cannot be transferred onto the total population.

tend to favor patients with a biomedical understanding of HIV and AIDS.[152] These practitioners may choose to provide more sympathetic treatment than they would to patients whose understanding of the disease is distinctly non-biomedical. This may support a stable relationship between medical staff and the first type of patient and an instable relationship with the latter, rejecting the often paternalistic structured medical system in Tanzania.

Dilger (2005:330) mentions, the assurance of being HIV-seropositive needs to come along with the identification of the biomedical model of disease in Southern and Eastern Africa. But according to him the opposite is the case, as manifold indigenous concepts of diseases in the context of AIDS evoke.

On the one hand, different explanatory models of disease in fact seem to exist in a parallel manner. This is vividly apparent in the statement given by Elisa in Chapter 7.3.1 and confirms Dilger's statement (2005:330). She believes the disease is either God given (God's world) or the result of witchcraft, referring to the present world.

Interestingly, Elisa clearly says "traditional healers are liars", doubting her explanatory model of disease after receiving her results and instead puts deep trust in ART and therefore biomedicine. Nevertheless, this statement does not deny the existence of witchcraft.

However, the results of the biomedical terminology used and the growing trust in biomedical treatment may show a change in disease perception. Biomedicine wields powerful influence, and although indigenous and biomedical concepts overlap, biomedical conceptions of disease appear to undercut and devalue indigenous beliefs.[153] As noted by Ashforth, Southern African generations have experienced drastic change amongst others affecting their knowledge systems (2010:58) to which explanatory models of disease certainly belong. As the results show, different explanatory models of disease such as *God's world*, *the world of here* (i. e. witchcraft) and *biomedicine* are differentiated, though able to exist simultaneously alongside one another, as emphasized by Elisa and serving as a strong evidence for diverse explanations of disease in Tanzania.

Trust in the power of God is made clear by Halima, Elisa and Rose, who all mention that disease is a God given destiny and evasion is impossible. Elisa even goes further and argues that all of her actions lie in God's hands, assigning all responsibility of her behavior to God. This statement gives powerful evidence for the strong influence of religion on concepts of destiny and life in general and implies the possibility to escape any responsibilities, carrying an inherent danger.

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[152] Experiences of favoring patients with a biomedical explanatory model of disease versus patients explaining disease through witchcraft while working at the hospital in Tanzania were personally made.

[153] Here it needs to be considered that we have dealt with a selected group of women, who have already taken the step to get tested and who have visited the clinic for further treatment, having attended at least one adherence class at the clinic and one medical check-up prior to the interview.

In the context of the strong religious beliefs with a powerful God judging and leading their destiny none of the interviewees mentioned HIV as a God given punishment for bad behavior and immoral lifestyle. This contrasts Dilger's findings of the Luo where HIV was seen as a punishment from God (Dilger 1999:43, 2005:39).

Again referring to psychological theories religiosity is a known coping mechanism in dealing with a disease and illness and may be overrepresented in this sample. Additionally one has to take into account various methods of comprehending the illness, such as the concept of *Sinngebung,* as a coping mechanism, meaning that the disease is to be used to lead a morally better life (Heim and Perrez 1994).

Concerning *illness* nearly all women were tested for HIV when already suffering from severe sickness. The experience of being ill was reported differently among the women but Rose's testimony was the most dramatic, describing the terror of her illness.

Strikingly none of the women talked about getting tested for HIV but instead used the term *to check the health status.* Hereby direct association with HIV and a possible infection may be avoided or even denied, leaving open possible other reasons for them being ill, thus embodying the silent language in the context of HIV.

Interestingly it was mentioned by the interviewees that Swahili families tend to hide ill family members. This might be explained by welfare towards the person affected offering them a quick recovery, but also as a protective behavior by the family protecting the patient (and the family itself) from inquiries and possible discrimination by outsiders.

Due to not only being chronically ill the interviewees were emotionally troubled, fearing negative financial consequences and existential fear. Rose told us that after diagnosis she began arranging her future burial. The costs for caring for a patient are often less than the burial itself, while funerals impose a heavy financial burden on the family, often leaving them in debt (Dilger 2005:137-138).

Halima was also worried about who would care for her children upon her death, which would be another financial burden for family members. Her fears highlight the impact of the disease on the lives of the infected, their families, the community, and society at large.

During data collection I noted the frequent usage of the term *normal* in the context of HIV and AIDS. In this context the use of the term *normal* can certainly partly be understood as a coping mechanism. On the one hand *acting normally* minimizes the attention given to the daily life of the infected person as well as in the form of denial and the surrounding society. As if being *normal* and trying to join the majority could possibly protect that person from being discriminated against by society. As Goffman argues, the affected person trying to live the life of a *normal* needs to be aware of their role as a discredited person and the associated stigma (1979:56), concluding that the women interviewed certainly bear aspects of self-stigmatization.

Yet another facet of the term *normal* in the context of HIV has to be discussed. Referring to Link (2009:39, 111-112) *normalities* underlie a dynamic process. In Tanzania, where one out of twenty people are infected, implying that a high number of people are indirectly affected, helps HIV to pass for a usual and therefore *normal* disease as vividly described in Chapter 7.3.1 by Halima. A statement underlined by Rose in Chapter 7.3.1, comparing HIV and AIDS with having fever and the destiny of a car accident.

Whether this handling of the disease is a consequence of the availability of ART leading "…from the transformation of a 'death sentence' to a 'manageable chronic condition'" (Ashforth 2010:58; emphasis in original), the influence of medical institutions and possible superimposition of language in use, a greater knowledge of the disease, rising numbers of people affected or a combination of all factors, needs to be further addressed. The development of the language in use talking about HIV can be seen as a favorable way to cope with the disease, yet at the same time the behavior following needs to be assessed in future studies.

8.2 Interpretation of results concerning discrimination and (self-)stigmatization

Strikingly every single woman interviewed has had multiple experiences with various forms of discrimination. Many have experienced verbal discrimination through rumors and direct verbal attacks such as prediction of an early death. Others reported of segregation in daily life such as their participation at ceremonies.

This form of discrimination may serve the effect of confinement between the bearer and non-bearer of the stigma. This could be perceived as necessary for the persons close to the affected in order to protect themselves from associated affects in the form of possible discrimination.[154] While most of the women reported of rumors and segregation by distant people, Halima reports of direct segregation of her HIV-seropositive aunt by her family, contradicting the statement given by Kleinman, that normally discrimination is not performed by close family members (1988:160).

Interestingly most of the women referred to the term *finger pointing* as a matter of discrimination and as vividly illustrated on the cover of Dilgers book *Morality, Hope and Grief* (2010). Pointing a finger on a person marks and excludes them from the person pointing, calling attention to their *otherness*.

Women also reported of accusation of adultery or prostitution, assigning them to a marginal group of society. Their infection is hereby judged by

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[154] For further information see Herek (2009).

misbehavior of the person affected (Sontag 1989:28), titled by Kleinman as the “stigmata of veneral sin” (1988:21) and a form of discrimination automatically leading to a devalued perception of the individual and questions of blame and subsequent distribution of guilt (Charmaz 2000:284), morally judging the individual.

According to Dilger, the position of the non infected is as follows: “…the disease is often seen from an emic perspective, as a marker of disorder and chaos which has to be acted upon in order to arrive at social and moral coherence” (2010:10). In this case morality refers to the central value structure of a society (Dilger 2005:37). Dilger noticed that it is “…mostly specific subgroups of the population – often women (…) – who are seen as indicators of these moral ruptures. Thus, (while) HIV/AIDS is seen in many African countries as a general signifier of deviance…” (2010:10).[155]

Interestingly Neema reported of people accusing her of *pretending* to be positive in order to receive support. Here she is accused not only of lying but exploiting the HIV-seropositive status in order to positively profit from it – in this context the question of blame has turned. She is not blamed because of the illness, but instead of pretending to be sick and exploit others – the societal threat of the disease is provided by those fearing infection, which might be an unconscious coping strategy, although she is accused of being an immoral person.

Self-stigmatization was only rarely and indirectly mentioned during the interviews, therefore interpretation is limited. Here one might speculate whether the women suffer from very limited self-stigmatization, possibly due to being involved in a clinical setting and being educated concerning HIV by the CTC, or whether the topic was not talked about due to guideline questions or the interview situation in general. However, self-stigmatization may not be directly reported because the infected may not be aware of it and it may be difficult to directly address this issue in an interview.

Nevertheless it can be presumed that self-stigmatization occurs. For example, some of the women reported the need to hide their medication and pill taking. This may be evidence of this need in order to belong to the *normals*. Thus evident that she has internalized being *abnormal*, due to discrimination, following self-stigmatization. Women additionally emphasized the need to be, feel and live *normal*. This may either show their feeling of actually *being or having been abnormal* or *being labeled as being abnormal* through discrimination, therefore having this need to not be excluded from the majority.

Halima directly referred to self-stigmatization when she referred to the rejection of her relative and when she felt she was being seen as a prostitute, while Elisa was hiding after receiving her test results, possibly due to internalized experiences of discrimination and thus self-stigmatization.

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[155] Please see also Dilger (2005:36) and Weiss, Ramakrishna and Somm (2006:280-281).

Although Mariamu stated that she is not experiencing discrimination, it is astonishing that she emphasized of being HIV-positive as describing herself of being an "HIV-infected person" (Section 238). Whether she wanted to emphasize, that she will never be part of the majority because of being infected, or nonetheless stay part of the peer group having overcome self-stigmatization, will remain undetermined. Concluding and by examining the results presented here, interpretation of results concerning self-stigmatization has to be conducted with caution.

9. Conclusion and the Way Forward

The aim of the chapters ahead was to shed light on the profound influence of HIV and AIDS onto the lives of people infected and their social environment in Tanzania, focusing on discrimination and stigmatization in the context of HIV and AIDS, firmly linked to illness and disease. The interviews conducted with HIV-seropositive women at the BRH in Tanga present the experiences of women and highlighted the many issues patients face.

As this book is embedded in the discipline of public health and applied medical anthropology it seemed necessary to briefly enlighten the reader as to development and current status of medical anthropology as an important and emerging sub-discipline of anthropology itself.

As shown, HIV and AIDS in Tanzania is a tremendously influential disease affecting the cultural, social, individual, political and economic status of individuals and societies. Thus, a chapter dedicated to the international reactions to HIV and AIDS, as well as the handling of the disease in Tanga city was included, continuing to describe the historical national political response in the context of HIV and AIDS of Tanzania, as well as the mounting discrimination and stigmatization.

Focusing on illness experiences by HIV-seropositive women in Tanzania and their explanatory models of disease, an important differentiation between the terms of illness and disease was made in accordance to Kleinman (1988). Hence, illness can be seen as an interpretation and expression of pathological bodily symptoms, while the concepts of disease, illness and pathology are culturally bound and shaped and differ from *the western biomedical concepts* as shown by the interview results. Anthropologists particularly question the biomedical universal construction of disease and aim to focus on illness experiences as the cultural expression of bodily symptoms. Illness is acting as a "…violation of the general order" (Augé and Herzlich 1995:7) calling "…into question the environment in the broadest sense of the word" (Augé and Herzlich 1995:2), showing the influence of illness and the importance to focus on illness.

Numerous authors have dealt with the topic of stigmatization and discrimination in the context of illness and particular in the context of HIV, although terms are often used interchangeably. Before discussion on the topic, these terms must be clearly defined. Within this book Geiselhart's determination of discrimination and stigmatization were used as orientation (2009). While discrimination explicitly referred to actions, stigmatization was rather defined by abstract themes and general attitudes. Additionally the term self-stigmatization was used, referring to internalized stigmata by the individual. While a stigma is most often seen as a negative attribute, Geiselhart (2009) stresses that a stigma given can be of a negative or positive character for the bearer and can be internalized or rejected (2009).

The observation of dialogues with infected women concerning illness and disease in a hospital setting showed that the terms *normal* and *abnormal* especially in the context of illness and disease play an important role, ranking persons into a hierarchy in society. These persons are then either marginalized or included. Especially in the context of chronic illness coping strategies may become an important tool to deal with disease while integrating the disease into daily life, *making it normal*, as exhibited by the women interviewed. Other individuals may attempt to escape discrimination by joining themselves to the majority, trying to act and *be normal.*

But not only people directly affected constantly judge normality and abnormality. Those indirectly impacted also analyze and judge illness within their framework of *belonging* (or not) to the societal majority. In doing so, and in order to secure one's place among the powerful, and to access the security that belonging to the majority provides people tend to discriminate those who threaten the group. HIV – until now a dreaded, incurable, and infectious disease – therefore represents a continuous threat to non-carriers.

So far no adequate health system oversees full care of the sick in Tanzania and von Goethe stating "…in times of hardship one needs its family"[156] (1926:XI:210) proves true. In Tanzania close family members of the sufferer most often take on the role of the caregiver for the sick person. The role of the family in caring for the sick is rarely questioned, nor is it replaced by anonymous medical practitioners in clinics or hospitals as is happening in high-income countries. In this context discrimination is mainly enforced by distant relatives or people outside of the immediate family ties as observed by Kleinman (1988:160) and shown within the results of this book.

As claimed by several authors an ethnographic approach is the most appropriate method for collecting data on *disease* and *illness,* as conducted in this study, although limitations have to be taken into account.

The validity of the answers given can be critically questioned including the choice of research setting, the recruitment of participants and the study sample.

First, patients visiting a governmental owned hospital instead of a private health clinic in Tanzania, already present a selective group of participants considered for the study.[157] Second, due to heavy workload for the doctors, and irregular attendance of AMOs, the study sample may be biased since recruiting staff may have asked only seemingly suitable patients to participate. Therefore we might deal with a convenience sample in the contrast to a full population survey. Third, as interdependency between the patient and the doctors exists, patients might have felt possible pressure during the recruitment phase, hence involuntarily agreeing to be interviewed. Fourth, during the questionnaire and interview

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[156] The original citation in German is the following "Denn zu Zeiten der Noth bedarf man seiner Verwandten" (von Goethe 1926:XI:210).

[157] Close to the Bombo Regional Hospital, *Safi Medics*, a privately owned hospital is located.

session, *social desirability* might have lead to an *acquiescence effect* in respondence, leading to a falsification of the results acquired.[158] Finally, a bias might have occurred, due to the seeking of a biomedical treatment in a clinical setting and social interaction between medical staff and patients.

Thus, prior to the commencement of the study we attempted to minimize and eliminate some of the factors listed above, while others could however not be changed. At the very beginning of recruitment an emphasis was put on ensuring voluntary participation by training the AMOs, who would later recruit study participants. Additionally we provided confidentiality in securing anonymity, clarifying the study procedure, reading and handing out copies of clearance and consent forms to the participants and finally asked for the reason of participation at the end of each interview. Unfortunately, due to the topic of the study concerning disclosure and without further extraordinary costs, no alternative research setting than the hospital could be chosen, protecting the interviewees from involuntary disclosure.

Due to the use of transcripts, criticized by Sabine Kowal and Daniel O'Conell as "theory-loaded constructive processes" (2004:249), while data was voice-recorded, transliterated and translated, a possible loss or falsification of data needs to be accounted for.

Concerning the analysis of the data presented, no distinct passages of the interview ascribed to the definition of stigmatization could be coded, in contrast to self-stigmatization and discrimination. This might be due to the research design, not explicitly focusing on stigmatization and discrimination and its definition of rather abstract themes and general opinion.

Concerning the results it was remarkable that every woman interviewed reported of *getting her health status checked*, not referring to the HIV-test directly starting a careful and secretive dialogue about the topic of HIV and AIDS, as described by Mogensen (2010) and elucidated in a previous chapter. At the time of testing nearly all women were already suffering from sickness – an alarming fact and logical starting point for further investigation in the context of epidemiological concerns and the development of support strategies.

On the other hand the women interviewed have confidently used biomedical terms while describing their disease, which may be influenced by several determinants, such as the research setting and/or social desirability and/or rising availability of information on HIV and AIDS from a biomedical perspective. Whether this is due to increased education on HIV and AIDS provided by the hospital or the environment in general remains an unanswered question.

Interestingly, several explanatory models of disease exist unquestioned in a parallel manner, as mentioned by Dilger (2005:330), although explanatory models such as *traditional healers* seem to be questioned, possibly signaling a change in

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[158] For further information on social desirability and an acquiescence effect with questionnaires the further article by Hinz et al. (2007) can be recommended.

perception. Concepts of disease and perception of disease should be addressed in further studies as knowledge about these concepts surely contributes to the issue of how to implement effective prevention and support strategies.

As explained earlier, the results may not represent the average Tanzanian population. As women are bound to a clinical setting, regularly being educated about and confronted with the biomedical concept of the disease, it may be hypothesized that the general population is faced with discrimination and stigmatization in the context of HIV and AIDS to a larger extent than our study sample and explanatory models of disease may differ.

As seen within the prior chapters discrimination and self-stigmatization in the context of HIV is generally omnipresent – not only at the level of international politics, but as experienced by the women interviewed in Tanzania, although a declining trend in Western countries can be observed (Kleinman 2011).

Women reported segregation and found themselves to be the target of offensive gossip, finger pointing, and were faced with accusations of adultery or prostitution almost explicitly committed by distant relatives, as also noted by Kleinman (1988:46).

The explicit reference of the word *normal* in the context of disease can on the one hand be seen as favorable to the women affected (compare to Dilger 2010:11). Women seem to have developed a coping mechanism, thus they are aware or unaware of their attempts to remain integrated in society. The tremendous number of people being directly or indirectly affected by the disease with a prevalence rate of six to seven percent (Charmaz 2000:282) might have an additional impact on this attitude, as well as the availability of ARVs, therefore leading to a comparison with a common disease such as Malaria (Rose, Section 18) or developing a fever (Rose, Section 88).

On the other hand this development can be seen as tremendously alarming. Women strain themselves to behave as though they were living a *normal* life in order to protect themselves, as well as their immediate family, from discrimination and stigmatization. This requires them to simulate normalcy, possibly leading to conflicts, as they may prefer to not ask for support despite their illness, or worse, not take precautions to avoid spreading the disease to others. As in Tanzania no adequate health care system exists and most people are dependent on their family members' care and financial support throughout their illness (see Figure 5), it is apparent that rejection from their families may mean a threat to their existence.

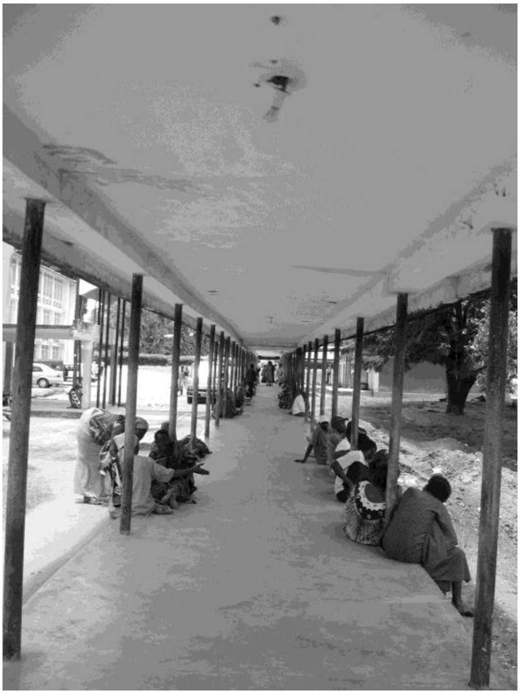

Figure 5: Patients and relatives caring for in-patients waiting in front of the departments of the Bombo Regional Hospital for entrance during visiting hours (Personal photo, 2007).

Nevertheless, it could be illustrated, that HIV-positive women are highly discriminated against, not only in Tanzania but worldwide and not enough is happening to reduce discrimination and stigmatization in the context of HIV, while successful implementation of the current legislation is missing. Even in 2011 people with HIV are deprived of human rights such as the right to move freely throughout over 50 countries worldwide, constantly fearing discrimination and stigmatization in daily life.

The dimension of the disease is summarized by Dilger, who writes

> *"… the disease has affected local and household economies; gender and kinship relations; religious expression and organization; conceptions of life, death and healing; and the organization of social, cultural and political life in sub-Saharan Africa in general"* (2010:3).

However,

> *"… the strong focus on life-worlds that are promoted and represented by nongovernmental organisations and humanitarian interventions represents only a partial*

> *view of the complex social and cultural processes that have come to shape the social reality of HIV/AIDS in sub-Saharan Africa"* (Dilger 2010:11).

Ethnographic research is crucial in addressing the need to better understand the complexity of the disease and its enormous impact in numerous aspects of daily life in order to implement appropriate action in the context of HIV and AIDS.

In order to effectively address discrimination and stigmatization in the context of HIV, as well as to better understand the spread of HIV one has to consider the culture specific explanations of illness and disease as observed in Tanzania. The illumination of concepts of illness and disease from a medical anthropological point of view is certainly important, while in the long run a multi-methodological approach should be encouraged. Furthermore, prior to discussions, terms such as discrimination and stigmatization need to be defined in order to have provision debate on the basis of comparable data.

Future research should also concentrate on the development of the use of the word *normal* in the context of HIV. While campaigns once focused on the incurability of HIV, hence causing fear and threat, ARVs have tremendously influenced the course of HIV from a death sentence to a "manageable chronic condition" (Ashforth 2010:58). Whether the availability of ART will alter the perception of and conversation about the disease in Tanzania and/or possibly creates "…new forms of careful speech that transgress the dichotomy of hiding and disclosing" (Ashforth 2010:51-52) remains to be seen.[159]

While this study has focused on women infected by HIV it could be of interest to change the angle of the focus in future research to better understand reasons and patterns of discrimination in the context of HIV concentrating on the uninfected population actually engaging in discrimination.

When we asked Halima on why she had agreed to be interviewed she answered:

> *"Why I agreed to be interviewed? I agreed to be interviewed after seeing that this is not an issue which just concerns us who are infected with the virus, because there are so many people! Maybe eighty percent of the population still stigmatizes (i.e. discriminates) patients who are infected and now the doctors don't know and even the government doesn't know! So this is the place where we get effects and we do not have any way of condemning this behavior"* (Section 236).

As Halima demands, advocacy for the people infected is needed while an open dialogue needs to begin. When Nelson Mandela declared the death of his son in

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[159] For further information on ART and the possible change of disclosure, perception of HIV and behavior see Mogensen (2010). Whether the quality of dialogue in Tanzania will change due to life-extending medication by increased disclosure and the loss of its threatening character (Castro and Farmer 2005:57-58) or the exact opposite will happen as the need of disclosure diminishes remains unknown. With the availability of ARVs in Tanzania further long-term research is needed on the development of the dialogue in the context of HIV.

2005 as a consequence of AIDS he claims: “Let us give publicity to HIV/AIDS and not hide it, because [that is] the only way to make it appear like a normal illness” (BBC News 2005:n.p.; Comaroff 2010:26). However, a change of perception may arise not only by ending the silence, but in the reduction or even disappearance of the frequent usage of metaphors by the carrier and non-carrier. Kleinman’s statement, referring to discrimination in the context of mental illness, can also be transferred to the context of HIV, demanding a “…cultural change (which) is fundamentally a moral change...“(Kleinman 2011:n.p.).

HIV and AIDS has become a matter of human rights. International organizations claiming to advocate for the people affected might accidently contribute to discrimination since they do not call into question the military-like language used to describe the disease and the concentration on homosexuality and sexual intercourse as the most common mode of infection. Therefore I want to support Halima’s demand and close with Herek’s calling, turning to the dictum saying:

“Fight AIDS – Not People With AIDS!” (2009:n.p.).

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Appendix

Diagrams

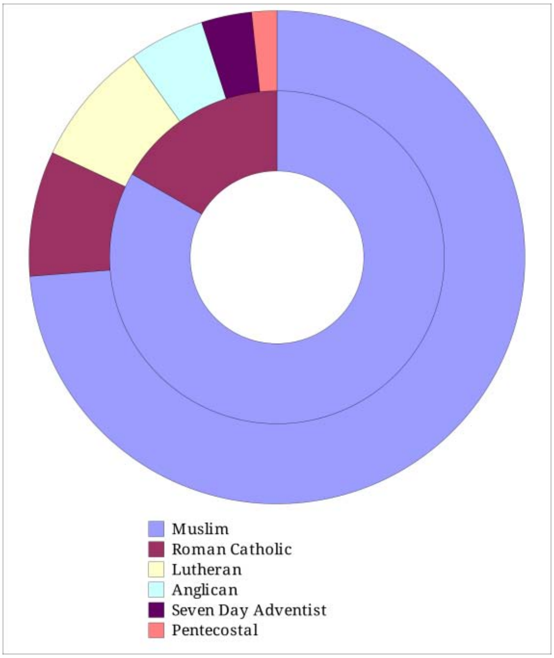

Diagram 1: Illustration of religious affiliation of all women interviewed in the outer circle (n=61) and religious affiliation of interviews presented in the inner circle (n=6). Diagrams were created using the open-source software Gnumeric Tabellenkalkulation 1.10.8[1] (The GNOME Project 2011).

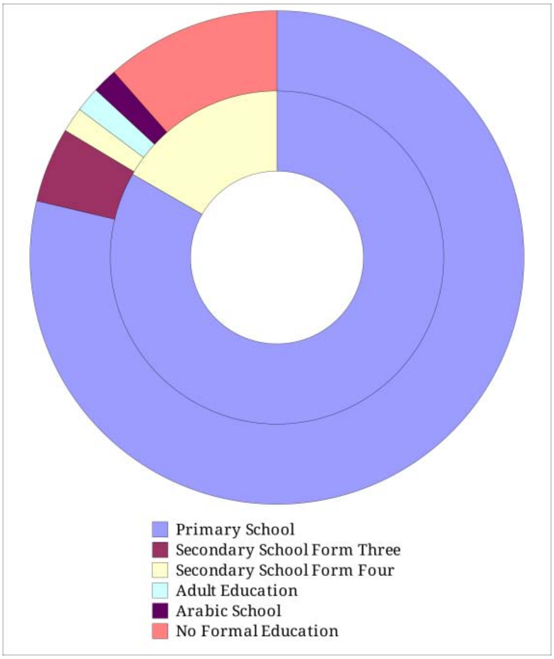

Diagram 2: Illustration of educational level of all women interviewed in the outer circle (n=61) and educational level of interviews presented in the inner circle (n=6). Diagrams were created using the open-source software Gnumeric Tabellenkalkulation 1.10.8[1] (The GNOME Project 2011).

Tables

Table 1: Ethnic belonging of the participants

Ethnic belonging of interviewees	Interviews not analyzed (n)	Interviews analyzed here (n)	Interviewees total (n)
Msambaa	13	0	13
Mdigo	9	1	10
Mpare	1	1	2
Mchaga	3	1	4
Mgunya	3	0	3
Mzigua	2	0	2
Msangu	1	0	1
Muhehe	2	0	2
Mbondei	5	2	7
Msukuma	1	0	1
Muha	1	0	1
Mnyamwezi	4	0	4
Mshihiri	1	0	1
Mpogoro	0	1	1
Mmakua	2	0	2
Mmakonde	2	0	2
Mmanyema	1	0	1
Mngoni	2	0	2
Mmanda	1	0	1
Mzaramo	1	0	1
Sum (n)	55	6	61

Table 2: Religious belonging of the participants

Religion of interviewees	Interviews not analyzed (n)	Interviews analyzed here (n)	Interviewees total (n)
Muslim	40	5	45
Roman Catholic	4	1	5
Lutheran	5	0	5
Anglican	3	0	3
Seven Day Adventist	2	0	2
Pentecostal	1	0	1
Sum (n)	55	6	61

Table 3: Level of school education of the participants

Level of school education of interviewees	Interviews not analyzed (n)	Interviews analyzed here (n)	Interviewees total (n)
Primary School	43	5	48
Secondary School Form Three	3	0	3
Secondary School Form Four	0	1	1
Secondary School Form Six	0	0	0
University Certificate	0	0	0
Adult Education	1	0	1
No Formal Education	7	0	7
Arabic School	1	0	1
No answer	0	0	0
Sum (n)	55	6	61

“She was given her own plate, her own cup, everything of her own,
even when she just touched a cloth then nobody wanted to touch it again.”

(Halima, HIV-seropositive)

The book sheds light on the profound influence of an HIV-seropositive diagnosis on the lives of women and their social environment in the United Republic of Tanzania. The author, a medical doctor and social anthropologist, tells the story of six Tanzanian HIV-seropositive women, focusing on their negotiation and perception of illness and disease. Furthermore, the high levels of discrimination and stigmatization in the context of HIV-seropositivity that they experience are presented in detail, weaving together the impacts of an HIV-seropositive diagnosis with results analyzed both from a Medical Anthropology and Public Health perspective. Despite a new era of antiretroviral treatment, available in Tanzania free of cost, that has given cause for hope in a change in how the disease is perceived, the book impressively underlines that being HIV-seropositive remains a great challenge and heavy burden for women in Tanzania.

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