Hochschule für Angewandte Wissenschaften Hamburg
Hamburg University of Applied Sciences

Hamburg University of Applied Sciences

Faculty of Life Sciences – Health Sciences Degree

Individual Coping by HIV-positive People with Non-Infectiousness due to Successful Antiretroviral Therapy

Master Thesis

Date of submission: 06.11.2014
Submitted by Björn Trenker
Matriculation Number: 2129706
Examination supervisor: Prof. Dr. Christine Färber
Secondary supervisor: Dr. Dirk Sander

Abstract

Background: Antiretroviral therapy (ART) surpresses the viral load of HIV under a detectable level and reduces the risk of HIV transmission. Consenting HIV discordant partners who do not have other sexually transmitted infections (STIs) can have safer sex without condoms if the HIV-positive partner is on effective ART for at least six months and regularly checked. The protective effect is comparable to the use of condoms. This effect was first openly communicated in 2008 by the Swiss Federal Commission on Aids-related issues and subsequently adapted by Deutsche AIDS-Hilfe e.V. (DAH). The subject led to assumptions about a theoretical decline in protective behavior, but also to a possible reduction of HIV-stigma. This study focuses on the behavioral and psychosocial effects of non-infectiousness and individual coping.

Methods: A qualitative study design with in-depth interviews and a hermeneutic phenomenological analysis approach was conducted. The heterogeneous sample contained 17 HIV-positive women and men who were diagnosed HIV-positive over the last 20 years and started ART between 1999 and 2013.

Results: Eight categories associated with individual coping could be developed. The understanding and acceptance of non-infectiousness varied individually. In regard to the HIV regimen and HIV stigma, adjusting to life with HIV was a challenging experience for the participants and, in regard to their circumstances and the history of HIV, the process of accepting a non-infectious HIV corporeality was subject to dissonance between rationality and emotionality. Reduced internalized HIV stigma was indicated by less fear of HIV transmission and a regained sense of well-being. Half of the participants have practiced medical therapy as a protective method at least once, notwithstanding gender, age, cultural background or sexuality. Among men who have sex with men the importance of serosorting as a protective method and the relevance of STIs increased. Among women the possibility to have children was essential. A lack of information on non-infectiousness in the medical setting and a lack of awareness in society also became apparent.

Outlook: As this is an explorative study, the results provide a framework for further research on this subject, especially in the context of HIV stigma. A rational and realistic instruction of People Living with HIV (PLHIV) within the medical setting and a raise of public awareness are recommended.

Table of Contents

Table of Figures

List of Abbreviations

ART	Antiretroviral Therapy
DAH	Deutsche AIDS-Hilfe e.V.
EKAF	Eidgenössische Kommission für Aids-Fragen
HPTN	HIV Prevention Trials Network
MSM	Men Who Have Sex with Men
PAFPI	Positive Action Foundation Philippines, Inc.
PEP	Post-exposure Prophylaxis
PLHIV	People Living with HIV
PrEP	Pre-exposure Prophylaxis
STI	Sexually Transmitted Infection
TasP	Treatment as Prevention

1. Introduction

“Manchmal schaue ich so auf meine Venen und denke mir, ja, da ist ja irgendwas in meinem Blut. Wie so ein Schatten, der einem immer im Nacken ist. Und gleichzeitig ist das ja nur ein Schatten und der nimmt trotzdem nicht überhand. Die Sonne kann doch durchscheinen” (Collin, 40-43). In a contemplative moment one of the participants described his impression of the ambivalent threat of the HIV infection in times of effective medical HIV therapy. The quality of life and the life expectancy of PLHIV have remarkably improved since the mid nineties due to medical and therapeutic developments. Until then, a positive HIV test result would challenge someone to face the prospect of an early death, as the typical course of an HIV infection had then been characterized by a symptoms-free period, followed by the occurrence of opportunistic infections and finally death. Today in industrialized countries HIV is regarded as a treatable if not curable chronic disease. Furthermore, ART has an impact on the infectivity of HIV. Due to a suppressed and undetectable viral load, the risk of transmission of HIV is reduced. In 2008, the Swiss Federal Commission on Aids-related Issues openly communicated this subject for the first time; the so-called Swiss Statement (Vernazza 2008). In this article, it was implied that besides the protective effect of an undetectable viral load there is an expected positive effect on stigma, more precisely internal stigma. After much deliberation, DAH adapted its safer sex rules in 2009 and thus under certain conditions protection by therapy was added to the preceding rules, which included protection by condoms during anal and vaginal intercourse as well as withdrawal before orgasm during oral sex (Deutsche AIDS-Hilfe 2009). Consenting HIV-discordant partners who both have no other STI, can use the so-called viral load method. In that case, the HIV-positive partner should be on effective medical HIV treatment and the viral load in the blood should be undetectable for at least six months. Thus, far less virus is present in other body fluids like semen and vaginal fluid. The medical drugs have to be taken regularly and its effectiveness needs to be frequently checked (Deutsche AIDS-Hilfe 2013). Nonetheless, this subject is discussed controversially among health professionals, activists and politicians. What is of concern is a hypothetical decline in protective behavior, which has of yet not been proven. In this context, it is of interest how HIV-positive women and men understand non-infectiousness and how they cope with it. Is non-infectiousness naturally accepted or are there any doubts? What are the positive or negative consequences that derive from an undetectable viral load? Are there changes in attitude or behavior?

In Germany the HIV incidence is highest among men who have sex with men (MSM). In 2012, there were an estimated 63.000 men living with HIV in Germany of whom 51.000

considered themselves as MSM. During the same time period approximately 15.000 women were living with HIV in Germany (Robert Koch-Institut, 2012). The recency and impact of the developments in therapeutical outcome and the opportunities they provide require analysis of the beliefs and behavior of those affected in the first place. It is this analysis that can provide profound knowledge in times of fundamental change.

1.1 Research Project at Deutsche AIDS-Hilfe e.V.

The master thesis is based on a research project that I conducted from October 2013 to March 2014 at DAH, a nationwide non-governmental German Aids service organization. DAH was founded in 1883. It is a German umbrella organization representing approximately one hundred and thirty regional institutions with the main office located in Berlin. The focus of DAH lies on structural prevention and health promotion in the field of HIV/Aids and other STI. Structural prevention includes behavioral and environmental aspects, as well as primary, secondary and tertiary prevention and health support, participation and emancipation. A further central aspect is empowerment of vulnerable groups. The project was supervised by Dr. Dirk Sander, the head of the division for MSM, and Prof. Dr. Christine Färber, Hamburg University of Applied Sciences (HAW). My subject of interest was the living situation of HIV-positive women and men that derived from medical improvements and subsequent public statements on non-infectiousness due to successful ART following the Swiss statement in 2008. The contexts of an HIV infection changed radically with medical treatment since 1996. However, due to the daunting history of HIV/Aids the public perception changed only gradually. There is a new landscape for HIV prevention and in general there is a need for an encouraging yet realistic approach towards HIV/Aids.

1.2 Research Question and Aim of the Master Thesis

The aim of my project was to explore the changes in individual perception and behavior due to an undetectable viral load and to come to a deeper understanding of the individual experience of non-infectiousness after being tested HIV-positive. Due to the complex and interdependent nature of the researched subject, individual coping with HIV was included in the project’s concept and interview guideline. The outcome of the interviews on this aspect is in line with previous studies. An additional aim of this study was to provide recommendations in the field of HIV prevention.

The research question is as follows: How do HIV-positive people individually cope with non-infectiousness due to successful antiretroviral therapy? From the angle of Public Health, mainly two factors are relevant in this context: stigma – more precisely internal stigma – and risk behavior. Both aspects are focused in this study.

1.2 Thesis Structure

The thesis is structured in six parts: First, the introduction and outline of the research project, second, the theoretical background that gives an overview of the project's background, third, the methodological framework, fourth, the presentation of the results, fifth, a subsequent discussion of the findings, and sixth, a short outlook.

2. Theoretical Background

Based on a comprehensive literature review, the theoretical background of the researched subject will be outlined in this section.

2.1 Literature Review

The literature research was conducted in two phases. The development of the study concept is based on a cohesive literature review on the online databases of PubMed and Google Scholar as well as consultations with research associates. The interview guideline (see Appendix, p. 88), is based on deductive categories, which derived from the literature review. I started the first literature review on PubMed using search terms such as “Individual Coping“, “Antiretroviral Therapy“, “Serodiscordant“, “Non-Infectiousness“, “HIV” or the combination thereof. The results were unspecific and/or insufficiant. However, the search term “Swiss Statement“ in combination with “HIV“ resulted in 11 hits. The outcome of this search proved to be most suitable, bearing in mind that the literature on individual coping with ART-induced non-infectiousness and its psychosocial effects is sparse. In addition, on Google Scholar the search term combinations „Swiss Federal Commission for HIV/AIDS“ and “Non-Infectiousness“ with 11 results as well as “Swiss Statement“ and “Non-Infectiousness“ with 15 results proved to be most effective, yet no additional publications could be added. For the catalogue of Verbund Öffentlicher Bibliotheken Berlins I had to specify the search by publication period and type of media. A search for books published between 2008 and 2014 with the term ”HIV“ resulted in 38 hits. I chose this publication period to focus on the era after the Swiss Statement to possibly include literature that is topic related. The literature research at Fachbibliotheken des Hochschulinformations- und Bibliotheksservices was similar as I was using the term “HIV“ in the same publication period, which resulted in 37 hits. No publicatons could be added for the development of an interview guideline.

A follow-up literature research on the basis of results was conducted on PubMed, Google Scholar and the Digital Library of Freie Universität Berlin. Further literature was hand sorted based on previous studies. I choose literature based on the criteria for my study, e.g. age, gender, setting, or topic-related issues. In the following, I will outline the theoretical background of my research, including individual coping with ART-induced non-infectiousness and its psychosocial effects, risk of transmission under effective ART and further medical information, HIV stigma and stigma theory, as well as protective sexual behavior and epidemiological information on PLHIV in Germany.

2.2 The Swiss Statement

In 2008, the president of the Swiss Federal Commission on Aids-related Issues Prof. Pietro Vernazza among other Swiss HIV experts published a statement on the non-infectiousness of HIV-positive people, who do not have any other STI and who receive successful ART. This was the first public statement on this subject. Here it was also emphasized that PLHIV who started ART but are not in a steady relationship should be informed about non-infectiousness due to ART by their physician, as this information might be a relief for HIV-positive persons, who tend to fear transmitting the virus to others. To decrease the risk of transmitting STIs, safer sex should still be advised for anonymous and occasional sexual contacts and patients should be on the look out for STI symptoms (Vernazza et al. 2008, p. 168).

After the Swiss statement was published, Prof. Geoffrey P. Garnett pointed out in a study that, while ART as a prevention measure might be effective on an individual level for couples, on the population at large the effect is prone to various influences, e.g. the unawareness of newly infected persons. He emphasized that diagnosis needs to be timely and for public-health reasons treatment should start early. Garrett pointed out that the statement nonetheless provides an opportunity for positive public-health messages, by promoting adherence to treatment and concern over other STIs (Garnett 2008). In 2010, Bayi Kuzoe-Liengme stated in a two-year follow up that there have not been any cases of HIV transmission observed and that it has encouraged the development of new prevention strategies focused on the use of ART (Kuzoe-Liengme 2010, p. 714).

Regarding this study it is of interest what emotional or behavioral consequences the content of Swiss statement has on the individual.

2.3 Individual Coping with ART-Related Non-Infectiousness

During the literature review, the explorative character of this study became evident. While there are numerous publications that cover the medical background of the research project, articles on individual coping strategies and/or psychosocial effects are rare.

Three articles that I found were relevant for the development of an interview guideline and further analysis. Asha Persson conducted two of these studies. Both draw on qualitative interviews with heterosexual PLHIV and their partners in Australia, before and after the Swiss Statement. The first one focused on the potential effects of the Swiss Statement on PLHIV. Besides a lack of information on the Swiss statement given by practitioners, the interviews revealed the complexity of sexual decision-making, stating that it is not solely based on prevention messages and research. Sexual decision-making was more complex, being shaped by dynamics around intimacy, stigma, gender, reproduction, emotions and relationship priorities, which implicated a necessity to contextualize the possible impact of the knowledge about non-infectiousness with these considerations in mind (Persson 2010, p. 1489-1490).

The second article addressed the change from infectious to non-infectious corporeality in the context of cultural and individual specifities and the history of HIV. However, these corporealities are not coherent and tensions became evident. It was revealed that HIV corporeality – clashing, for example, with life stories or gender dynamics – is rather complex and not a homogenized experience that follows a medical discourse. Infectiousness was not a cohesive experience and “the potentially liberating discourse of non-infectiousness was not automatically embraced or even necessarily relevant” (Persson 2013, p. 1075). The importance of “identifying and understanding […] the dissonances between biomedical rhetoric and people’s embodied experiences” was emphasized (ibid., p. 1076).

A third article by Daniela Rojas Castro focused on the awareness of the Swiss statement among PLHIV and potential, behavioral and emotional changes as a consequence of this awareness. Data from a community-based survey was used for this purpose. A significant lack of information on alternative prevention strategies especially in the medical setting became evident, as over 50 percent of the eligible participants in the 2010 biennial cross-sectional nation-wide survey found out about the Swiss statement not through their physician but rather via contact with HIV organizations (Rojas Castro 2012, p. 1016). Three factors proved to be beneficial: a better socioeconomic status, a controlled HIV-infection and integration in a community were (ibid.). The results showed a lessening in the fear of transmitting HIV and increased discussion about HIV with sexual partners, while sexual disinhibition was not observed (ibid., p. 1017). Overall, there appeared to be a minor but positive change in the quality of life (ibid., p. 1018).

In order to get a more comprehensive understanding of the research subject I consulted research affiliates Michael Bochow and Jochen Drewes. Bochow conducted the study “Schwule Männer und HIV/Aids” (in English: Gay Men and HIV/Aids) since 1987. This is a quantitative study on the living situation and the preventive and risk behavior of gay and bisexual men. Drewes conducted this study on behalf of the German Federal Center for Health Education (BZgA) in its tenth installment in 2013/2014. It became evident in these consultations that further studies, especially qualitative studies – for example on the psychosocial effects of this relatively new therapeutic situation for PLHIV – are of importance.

These previous studies on individual coping with ART-related non-infectiousness have implicated a lack of information in the medical setting, the complex nature of sexual decision-making and individual difficulties in accepting a non-infectious HIV corporeality, as neither infectiousness nor non-infectiousness were experienced in a cohesive way. Potential emotional and behavioral changes based on the knowledge about the Swiss statement were a decrease in fear of HIV-transmission and an increase in sexual communication as well as an increase in the overall quality of life.

2.4 Risk of HIV Transmission under Effective ART

When a viral load is under 50 copies/ml in a sample of blood it can be declared undetectable and the person can be regarded as non-infectious (Carter et al. 2014). Viral load blips are small increases in viral load up to 100 or 200 copies/ml. Vaccinations and infections can cause these small increases in viral load (ibid).

The subject of non-infectiousness due to ART is supported by scientific studies such as the HPTN 052 by the HIV Prevention Trial Network (HPTN) in 2011, after which it was concluded that the suppression of virus replication during a successful ART has the same protective effect for an HIV-negative partner as the use of condoms (Cohen 2011, p. 99). Subsequently, the international collaborative PARTNER study, which is currently coordinated by the Copenhagen HIV Programme (CHIP), aims to further fill the gap of accurate studies on the subject of impacts of HIV treatment on the risk of HIV transmission in serodiscordant couples including MSM (Rodger et al. 2012, p. 5). First results from the PARTNER study were presented in March 2014 at the Conference on Retroviruses and Opportunistic Infections (CROI 2014) in Boston and it was reported that there has been no transmission within couples so far and that the likelihood of transmission is estimated to be close to zero (Rodger 2014). The second stage of the PARTNER study, which aims to estimate the risk of HIV transmission irrespective of sexual practice, is planned for 2014-2017 (CHIP 2014). Additionally, the Opposites Attract study, a randomized controlled trial running from 2012 to 2015, is looking at relationships between HIV positive and HIV negative men (Bavinton 2014, p. 1).

Based on various studies, heterosexual infectivity of HIV in individuals taking effective antiretroviral treatment is perceived as low (Attia 2009, p. 5; Del Romero 2010, p. 5). The European AIDS Treatment Group (EATG) released a statement in February 2014 supporting treatment as prevention (TasP) and summarizing current scientific evidence. In this statement it was also revealed that, based on a number of observational studies, the transmission of HIV from people on suppressive ART via vaginal sex appeared to be a rare event (EATG 2014, p.5). Additionally, an unmet research need was mentioned considering transmission via anal sex, although a significantly reduced likelihood of HIV transmission under ART was suggested based on a combination of strong, direct and circumstantial evidence (ibid., pp. 4-5). Epidemiological evidence was mentioned, as observational and modeling studies indicated that in countries with high levels of ART access, the majority of infections come from people who are undiagnosed (ibid., p.5). Furthermore, the impact of STIs was addressed in the statement, mentioning that, if STIs raise the viral load in people who receive successful ART, it appears to happen seldomly to a level that would imply significant infectiousness (ibid., p.4). In terms of HIV superinfections, several studies show that cases of multiple HIV infections seem to be rare and do not compromise the efficiency of ART (Smith et al. 2005, p. 1; Bartha et al. 2013, p. 11).

Considering the legal situation in Germany, the intentional transmission of HIV is classified as an assault under German law – based on the paragraphs 223 and 224 of the German criminal code – and therefore punishable. In this context, the HIV-negative partner's awareness of the HIV-positive partner's status is relevant. It is not an obligation to inform sexual partners about the HIV status, as long as protective measures, e.g. condoms, are used. So far, German courts disagree on the question of whether or not an undetectable viral load is sufficient protection. In Switzerland, on the other hand, a consistently undetectable viral load is legally sufficient protection for the partner (DAH 2014a).

Based on these studies the protective effect of successful ART is comparable to the use of condoms and the likelihood of HIV transmission is extremely low. In this context, individual attitudes, considerations, worries or doubts are of interest, for example in regard to different sexual practices, viral blips, STIs, HIV superinfections, or legal matters.

2.5 Accommodating to the Status of Being HIV-Positive

In 1994, Jacqueline Lewis discussed the process of accommodating to living with HIV/Aids. She described various status passages in the transition of HIV-positive gay men from health to living with HIV/Aids. Each passage requires a period of adjustment and each new status becomes the central status in the person's life. In 1999, Lewis expanded the literature on status passages, focusing on the processes of accommodating to HIV and the associated socially stigmatized identity. According to her, PLHIV experience several status transitions with specific turning points and benchmarks. The HIV diagnosis can result in involuntary, irreversible and undesirable roles after being HIV-negative and accommodating to illness with subsequent identity changes. She observed that information, support and affirmation from others in a similar situation was seeked out in order to reconstruct identity, and that becoming a part of the PLHIV community was an attempt to end personal isolation and fight the associated stigma. However, these transformations are not necessarily experienced, recognized or acknowledged by every person. Lewis listed several characteristic dimensions of HIV-related status passages, including the centrality of each role, the shape, which is marked by turning points, the irreversibility, involuntariness and undesirability, the concealment, the number of passages, and the degree of awareness, for example, in the extent of conscious decision-making (Lewis 1999, pp. 94-110).

In a qualitative study in 2009 Lisa M. Baumgartner interviewed 14 adults aged 25 to 52 and described the incorporation of the HIV identity into the self as a three-step process marked by the diagnosis, a postdiagnosis turning point, and integration; a process similar to chronic illnesses. Central aspects are, for example, an initial emotional reaction to the diagnosis, help of support groups, educating others, and disclosure as a vital part to incorporation. Disclosure can be divided into three forms: disclosure to significant others, public disclosure and selective disclosure when necessary (Baumgartner et al. 2009, pp. 1732-1736). In a preceding qualitative study by Baumgartner, relating to a time when HIV was considered a terminal illness, participants reported on an immersion stage during which HIV/AIDS was a central identity, consisting of the HIV community experience, identity centrality and education by learning and teaching others about HIV/Aids (Baumgartner 2007, p. 924) In contrast, participants in the 2009 study claimed that their HIV identity was never central. This integration phase is marked by five components: experience in the HIV community, educating others, gaining support from outside the HIV community, time and health-dependent decentralization, and a change in the salience of other identities (Baumgartner et al. 2009, p. 1738).

In a paper she presented 2007 at the 8th International AIDS Impact Conference in Marseilles, Dr. Asha Persson discussed the difficult social, sexual and relationship challenges HIV-serodiscordant couples face and what role communication and silence play in coping with it. According to her report, which is based on a qualitative longitudinal cohort study, two opposite ways of coping – the sero-sharing and sero-silent mode – were functional for the participants in complementary ways (Persson 2007, pp. 5-6).

In regards to reproductive health, HIV does not seem to be a dominant factor in HIV-positive persons' desire for having children, as childbearing patterns, and reproductive determinants stay similar to those in the general population. Several studies, e.g. a European cross-sectional survey conducted by Simona Fiore, showed that, for many women, pleasure and happiness were tied to parenting with those who opt for children focusing on how to conceive safely (Fiore 2008, p. 2143; Nöstlinger 2009, p. 9).

According to these studies accommodating to life with HIV is a radical and potentially overwhelming process. It is of interest if and to what extent ART-related non-infectiousness affects this process and other dimensions in life, such as serodiscordant relationships or family planning.

2.6 HIV Stigma and Stigma Theory

The sociologist Erving Goodman referred to the term “stigma” as a discrediting attribute, which in society reduces a regular person to a “tainted, discounted one” (Goffman 1963, p. 3). Jennifer Crocker’s analysis of social stigma in 1998 attempted to normalize the process of stigmatization and the reactions of the stigmatized, which is an approach that might lessen it (Crocker et al. 1998, p. 543). Crocker approached stigma from the perspective of the stigmatized and therefore focused on the individual experience (ibid., p. 504). This approach includes the internalization of images and stereotypes, which can be approached in two dimensions: visibility and controllability (ibid., pp. 507-508). Crocker described certain characteristics of stigmatization, such as the function of self-enhancement for the individuals who stigmatize (ibid., p. 508). This is important in order to understand the persistence of stigma. Other aspects that are helpful to understand the nature of stigma are the widespread agreement on certain stereotypes, the ambivalence of those who are not stigmatized, discomfort or anxiety in social interaction, and differences between expressed attitude and actual behavior (ibid., pp. 511-513). According to Crocker, perceived stigma can be a threat to self-worth and the consequences for psychological well-being including an affected self-esteem or depression (ibid., p. 531). Another central aspect of Crocker’s approach lies on the potentially tense dynamics of social interactions between stigmatized and non-stigmatized persons in the wake of an increasingly open and diverse society. Ultimately, she points out essential elements of the discussion on stigma, which are the integrity of the self, the understanding of the world and the individual’s place in it, and the power of situations to shape experiences (ibid., pp. 538-542). Crocker’s approach on social stigma and internalized stigmatization illuminates the potential threats to the self.

Further studies focused on the impact of HIV stigma. Brenda Major described similar psychological effects of social stigma in 2005, referring to direct discrimination and indirect threats to the personal and social identity (Major et al. 2005, pp. 396-397). According to Major, stigmatized groups are at a greater risk for mental and physical health problems (ibid., p. 409). She emphasized the negative impact on important outcomes, such as self-esteem, academic achievements or health (ibid., pp. 412). The findings of Pilar Sanjuán’s survey in 2013, in which 133 HIV-positive volunteers participated, indicated an association between stigma perception and distress measures like anxiety or depression. There was also a reduction of well-being evident. Furthermore, stigma perception correlated with avoidant coping strategies, such as self-blame, denial, or substance use (Sanjuán 2013, p. 717).

In 2001, Bruce G. Link summarized that stigma exists when “elements of labeling, stereotyping, separating, status loss, and discrimination co-occur in a power situation that allows these processes to unfold” (Link et al. 2001, p. 382). According to Link, distinguishing and labeling is the first component of stigma. While most human differences are ignored and socially irrelevant, some are highly salient and therefore distinguished and labeled. To create groups, oversimplification is required. Social selections of human differences, however, differ according to time and place. Human differences are linked to stereotypes and associated with negative attributes. This can happen on an individual or a structural level (ibid., pp. 367-375). Ultimately, it takes power to stigmatize, as stigma is entirely dependent on social, economic, and political power (ibid., p. 375).

Jochen Drewes emphasized in his dissertation the significant role of perceived contagiousness as a crucial factor to HIV stigma. The findings of his experimental online study with a sample of 752 participants from all over Germany showed the potential of ART to reduce HIV stigma by lowering the viral load, if accompanied by a decreased perception of contagiousness. An impact on the willingness to physical interaction with an HIV-positive person could be measured, yet no impact on the willingness to social interaction, as this level was assumed to be already high (Drewes 2014, p. 3). The differentiation of physical interaction and social interaction is based on the distinction of instrumental stigma based on the fear of contagiousness and symbolic stigma based on moral judgements. This was, for example, explored in a 1998 two-wave telephone survey in the United States, which revealed that HIV/Aids-related stigma was prone to symbolic attitudes, while instrumental concerns were only relevant for a minority (Herek et al. 1998, p. 241).

In a qualitative study in 2009, which was focused on the concept of stigma, R.G. Block pointed out that individuals experience stigma differently and internalize differently, applying different coping skills and mechanisms. Nonetheless, the stigma experience was perceived as central in the lives of individuals with HIV, which was indicated by talking about feeling stigmatized, discussing changes in relationships after an HIV diagnosis, feeling scared of being discovered or outed and worrying about losing a job, a partner, a home or a family. The findings showed that at the core of managing and facing stigma was living with HIV (Block 2009, p. 16). Challenging life experiences like an HIV diagnosis are met with protective factors, e.g. support system, faith and previous success, and risk factors, e.g. depression or addictions. Some coping skills of the participants had short-lived effectiveness and negative consequences, e.g. drug use, denial, isolation, or maintaining low expectations. Healthy coping skills that were outlined in the study focused on taking care of oneself and engaging with others (ibid., pp. 12-15).

In 2008, Anish P. Mahajan outlined the devastating impact HIV-related stigma can have on the familial, social, and economic lives of individuals, potentially being a barrier to accessing prevention, care, and treatment services. According to Mahajan, there is a difficulty in measuring the extent of stigma, which is rooted in the variability in manifestations of stigma by cultural setting and level (Mahajan 2008, p. 11).

Peter J. Smit focused on MSM in a 2011 review of the literature, stating limited information on the impact of HIV-related stigma within communities of gay men. The findings revealed a division between HIV-positive and HIV-negative MSM, and a fragmentation of gay communities. In this context, HIV stigma incorporated aspects of social exclusion, ageism, discrimination based on physical appearance and health status, rejection and violence. The consequences can be traced on a personal and a communal level, including impacts on mood and emotional well-being, prevention, testing behavior, as well as mental and general health. According to Smit, the reduction of the gap between HIV-positive and HIV-negative men can lead to an increased well-being of HIV-positive men and improved knowledge about HIV-transmission and about what it is like to live with HIV among HIV-negative men (Smit 2011, pp. 3-5). In 2014, based on the narratives of 19 MSM in a southern U.S. city, Rigmor C. Berg reported on predominant internal stigma among the participants and intense stigmatization within gay communities. A division of HIV-negative and HIV-positive MSM was present. According to Berg, this can result in a “second closet” due to the increasingly invisible nature of HIV infections (Berg 2014, pp. 195-196).

In 2014, a report on the German project “Positive Stimmen” (in English: positive voices) was published online. A sample of 1.148 HIV-positive participants was surveyed on their experience with stigmatization and discrimination. Here the current impact of HIV stigma in Germany was outlined, e.g. 75 percent of the participants reported to having been depressed due to their infection the year before the survey (DAH 2014b, p. 38).

These previous studies have shown the wide-ranging and potentially threatening impact of HIV stigma on individuals’ life, environment and identity. ART-induced reduction of contagiousness and perceived contagiousness might have a lessening effect on HIV stigma, which is prone to symbolic attitudes and moral judgements. However, the question of how to measure the extent of stigma and the reduction of stigma remains. Further studies implicated a division within gay communities.

2.7 Protective Sexual Behavior

The findings of a qualitative study in 2013 in Spain reveal a separation of sexual responsibility in HIV-positive MSM in three courses: sole responsibility of the HIV-positive person to protect oneself and others, shared responsibility with an agreement on risk behavior, and individual responsibility where each person is responsible for his own. There were influencing factors mentioned, such as moral conscience, sexual context, type of sexual partner, or disclosure of HIV status (Fernández-Dávila 2013, p. 367).

Serosorting is the practice of having sex without condoms with partners of seroconcordant HIV status and using condoms with serodiscordant partners or those whose status is unknown, The study findings of Santos-Hövener in 2014 implied that having a direct and explicit conversation about HIV serostatus before sexual activity reduces the risk of acquiring HIV, bearing in mind that it cannot be the only measure and that in some settings, such as anonymous sex venues, it is not practicable. Besides the context of the conversation there are other influencing factors for the success of serosorting, for example, the HIV prevalence in the population, the explicitness of the conversation and the willingness to disclose HIV infection to a potential sex partner (Santos-Hövener 2014, p. 8). Santos-Hövener pointed out that in regard to the participants' risk calculation, most participants did not know about the low risk for HIV transmission during sex with an HIV-infected person receiving effective ART. He related this to the short time that had passed since the Swiss statement was published (ibid., p. 7).

In a 2010 literature review on serosorting and its implications for HIV transmission, which covered 51 studies, Lisa A. Eaton stated that serosorting and the urge to have sex with a partner of the same HIV serostatus can derive from various motivations, such as wanting to avoid HIV transmission, criminalization around HIV disclosure, stigma, or fear of rejection. Eaton stated that “serosorting allows HIV-positive men to remain sexually active and avoid condom use without the risk of infecting others” and that this might have had a positive effect on HIV incidence (Eaton et al. 2010, p. 2). According to Eaton's report many HIV-positive MSM assumed the HIV status of their partners to be HIV-positive (ibid., p. 3). A higher risk for coinfections with STIs was also stated. In regard to HIV superinfections, Eaton points out the particular concern deriving from a possible drug resistance, increased HIV virulence, or increased HIV infectiousness, but that a superinfection appeared “to be a rare event” (ibid., p. 3).

Ulrich Marcus described in a 2011 study, in which an anonymous self-administered questionnaire was distributed through German online sexual networking sites, the association of serosorting among MSM with increased self-reported incidence of bacterial

STIs, which could lead to a higher per-contact risk for HIV transmission. He stated that the patterns of HIV serosorting varied among HIV-positive and HIV-negative participants and that out of the 2985 respondents the majority expressed a positive attitude towards condom use for prevention of STIs other than HIV. (Marcus et al. 2011, pp. 5-6).

In the 2010 survey *Schwule Männer und HIV/Aids – Lebensstile, Sex, Schutz- und Risikoverhalten* (in English: Gay Men and HIV/Aids – Life Styles, Sex, Protective and Risk Behavior) – the ninth since 1987 – the sociologist Dr. Michael Bochow addressed a wide-ranging number of issues. The findings reveal that between 42 and 53 percent of all participants are bothered by the use of condoms (Bochow et al. 2010, pp. 277-278). For the first time in Germany, the question of sexual fulfillment was addressed, revealing a correlation between sexual happiness and increased sexual partners, with the exception of those participants who were in a steady relationship (ibid., pp. 144-145). Additionally, a correlation between consumption of party drugs (ecstasy, amphetamine, crystal, ketamine, mephedrone) and risk behavior was derived (ibid., p. 282). In comparison to the 2007 survey, the number of HIV-discordant risk contacts had doubled and among HIV-positive MSM 48 percent practiced unprotected anal intercourse with partners of unknown status (ibid., pp. 287-288).

These studies show that ART-related non-infectiousness brought up questions about sexual responsibility, sexual education and sexual conversation. Condom use was perceived as a valid protection method against further STI transmission. Furthermore, serosorting – a crucial subject among HIV-positive MSM – was discussed.

3. Methods

In the following chapter I am going to outline the methods that I applied during the research project and the analytic process. First, I will give the rationale for a qualitative research design and the phenomenological inquiry approach. Then, I will present the detailed study design, which includes an outline of the recruitment process, a sample description including the sampling process, an insight into the interview guideline based on deductive categories, a description of the interview situation and the transcription process as well as information on ethical considerations and the researcher's own experiences in the field of study in order to outline a potential influence on the research.

3.1 Qualitative Research

This project is an explorative study. The impact of an HIV infection on the life of PLHIV has drastically changed due to significant developments in medical treatment. In recent years the phenomenon of reduced infectiousness due to a medical drug induced undetectable viral load has caused a further shift in the lives of PLHIV. Since the Swiss statement in 2008 the phenomenon is highly topical and therefore needs to be investigated. From the angle of Public Health two main aspects are of interest. To what extent are stigmatization and self-stigmatization reduced? Does this have an effect on sexual risk behavior? Appropriate standardized methods to tackle these questions can be found in qualitative research, a scientific approach, which was employed in the fields of Psychology and Sociology since the early 20th century (Flick 2012, p. 30).

Consequently, I chose a qualitative study design in order to discover new aspects and/or theories on this subject. Whereas quantitative studies are useful to examine hypothesizes and, for example, the frequency and distribution of a disease, a qualitative approach is appropriate to examine the individual experience, as it is the case in this study (ibid., p. 41). According to Uwe Flick, the complexity of reality and phenomena calls for a methodological standard, which is open to this real-life complexity, whose cause and effect cannot be isolated in an experiment. The openness to the complexity of a researched object of this nature is one of the main characteristics of qualitative research in general, whereas in quantitative research this requirement cannot be met adequately (ibid., pp. 26ff.). Flick also points out the significance of individual perspectives and their multilayered complexity and diversity as another focus of qualitative research, which can be helpful to understand the behavior of individuals and their knowledge (ibid., pp. 28f.). A third characteristic of qualitative studies in general is the inclusion of the reflection of the researcher with regard to the researched object to the extent that not only the subjectivity of the participants but also the subjectivity of the researcher becomes a part of the research process. This stands in literal contrast to the approach in quantitative research, where the researcher is supposed to extract his subjectivity as much as possible (ibid., p. 29; Creswell 2013, p. 47). Ultimately, all these aspects separate qualitative research from quantitative research.

On another note, John W. Creswell defines a set of numerous characteristics of qualitative research based on four essential philosophical assumptions: Ontology, Epistemology, Axiology and Methodology (Creswell 2013, pp. 16ff.). The ontological question refers to the nature of reality and results here in the assumption of various realities by different individuals, more precisely the interviewees, who report their individual experience and perception on the same subject. The epistemological issue tackles the question of what knowledge is and how knowledge claims can be justified. In the research field during data collection the researcher of this study relies on the quotes of interviewees and information drawn from a comprehensive literature review. The axiological assumption refers to the values brought to the study by the researcher, which is approached here implicitly within the background and context description of the researched subject as well as explicitly in the explanation of the researcher's own experiences. The methodological issue is characterized by the researchers experience in data collection and analysis. The logic followed by the researcher is inductive and therefore the strategies in collecting data can be modified in the process if necessary. These general assumptions of qualitative research were taken into account in the development and process of this study.

To figure out what qualitative approach is most appropriate for the inquiry on the phenomenon of interest I applied the method of implication according to Flick (Flick 2012, p. 513). Considerations of the nature and aggregate of the phenomenon, my knowledge on the topic as well as my personal experience, my resources and my focus were helpful in the conduction of research.

3.2 Phenomenology

In the section above I outlined general features, which are common among all qualitative inquiries. However, each qualitative approach has its own distinctive focus and practices. For this study I choose to employ the hermeneutic phenomenological approach specified by Max van Manen in the 1990 publication *Researched Lived Experience: Human Science for an Action Sensitive Pedagogy*. Max van Manen is a professor emeritus at the University of Alberta in Edmonton, Canada.

Phenomenology is deeply rooted in philosophy and it is the study of the structures of experience and consciousness. Its origins go back to the early 20th century and it is based on the writings of Edmund Husserl. His ideas were discussed and further developed by his students and other philosophers, like Martin Heidegger, Jean Paul-Sartre or Maurice Merleau-Ponty (Creswell 2013, p. 77). There are different perspectives in phenomenology. However, they are based on common grounds: the lived experience of persons, the consciousness of these experiences and a thorough description of the essences of these experiences (ibid., p. 78). Essentially, two types of phenomenology can be distinguished: hermeneutical phenomenology and transcendental phenomenology. While the researcher's interpretations are a crucial part in hermeneutical phenomenology, which is Heidegger's alteration of Husserl's original ideas, the act of interpretation is less present within transcendental phenomenology (ibid., pp. 79f.).

Van Manen describes the phenomenological approach in doing research as an urge to become acquainted with the essence of human nature by questioning how the world is experienced (van Manen 1990, p. 5). In front of this background he emphasizes the uniqueness of each person's perception (ibid., p. 6). According to Creswell, phenomenological research aims for a description of "the common meaning for several individuals of their lived experiences of a concept or a phenomenon" (Creswell 2013, p. 76). Ultimately, through phenomenology "a deeper understanding of the nature of meaning of our everyday experiences" should be gained (van Manen 1990, p. 9). As van Manen points out, these meanings are not explicated to particular cultures, social groups, historical periods or mental types, as it is the case in other disciplines. Phenomenology rather attempts to "explicate the meanings as we live them in our everyday existence, our lifeworld" (ibid., p. 11). He concludes: "The aim of phenomenology is to transform lived experience into a textual expression of its essence." (ibid., p. 36)

Siegfried Lamnek states that in phenomenology a phenomenon is seen the way it is instead of the way it may appear based on precognition, preconception or theories, as the aim is to determine the universal and invariant essence (Lamnek 2010, p. 44).

According to van Manen, hermeneutic phenomenological research is characterized by six activities, as shown in Figure 3.1 (p. 24). First, the researcher turns to a point of interest, which indicates that the starting point of a phenomenological study derives from the desire of a real person to understand a particular aspect of human existence under certain individual, social and historical circumstances (van Manen 1990, p. 31). The researcher then investigates and explores lived experience while reflecting on its essential themes. Here van Manen emphasizes the profound progress of understanding the difference between the experience and the essence that grounds the experience in order to bring to light what otherwise evades our consciousness in everyday life (ibid., p. 32). The researcher then describes the phenomenon by the art of writing and rewriting. According to van Manen, the process of writing is an intrinsic part of phenomenological research, as doing research is always bringing something to speech (ibid.). During the whole process the researcher has to keep a strong and oriented relation to the object while avoiding superficialities and falsities (van Manen 1990, p. 33). Finally, the researcher has the obligation to balance the research context by repeatedly reflecting on the significance of single textual parts for the overall design of the study (ibid.).

1. Focusing on the topic of ART-induced non-infectiousness and its consequences
2. Conducting open interviews to investigate and explore lived experience
3. Developing and reflecting on the essential themes
4. Describing the phenomenon by writing and rewriting
5. Keeping a strong and oriented relation to the researched object
6. Balancing the research context in regard to singular parts and the whole

Figure 3.1 Applied Hermeneutic Phenomenological Research Activities

The researched object of this study is the experience of HIV non-infectiousness due to a medically induced undetectable viral load and how PLHIV are coping with this situation individually. I consider the hermeneutic phenomenological approach to be appropriate, because the phenomenon is fundamental to the life experiences of humans as it is centered on the quality of life with HIV/Aids. The severe and emotionally charged history of the fight against HIV/Aids and the multitude of influencing factors and dynamics in the life of PLHIV result in a complexity that can be met by this interpretative approach. Furthermore, the methodological procedures of hermeneutic phenomenology are appropriate for delivering a profound analysis and recommendations in the field of HIV/Aids prevention, which I ultimately aimed for after working for DAH.

3.3 Participants

For this study a diverse group of HIV-positive people, who receive medical therapy and whose viral load is undetectable, were interviewed. A list of sociodemographic data is included in the appendix (pp. 89-90). In the following section I will outline the recruitment process and a sample description including sampling practice, sample size and inclusion criteria.

3.3.1 Recruitment

Several organizations, persons and institutions were contacted for the purpose of recruitment. Among those were medical centers for HIV infections and other HIV related organizations. However, most participants were recruited through contacts in the departments of DAH. As I was recruiting mainly in Berlin, I aimed to not only include people who originate from a major city and thus, for example, have the opportunity to take advantage of good and comprehensive health and counseling services on site. In order to maximize the possibility of including participants with varied backgrounds, I presented the research project at the *Positiventreffen* (in English: Meeting for HIV-Positives), which took place from November 20th to November 24th at the Akademie Waldschlösschen in Reinhausen near Göttingen. The Positiventreffen is a nationwide educational workshop for all PLHIV in which current HIV-related topics are discussed and worked on. Besides these focus workshops, a variety of judicial, medical and health information, theatre and painting workshops, as well as trainings for volunteers in self-help projects are offered. The Positiventreffen is organized in cooperation with Deutsche AIDS-Hilfe e.V..

Personal contacts that could possibly add something profound to the study and that did not appear to be conflicting for personal reasons were also included in the sample.

3.3.2 Sampling

According to the concept of theoretical sampling I gradually defined the sample and data collection (Flick 2012, pp. 158f.). In order to gather maximum variation and cover a potentially wide range of coping practices, I aimed to create a heterogeneous sample of PLHIV. The sample could be extended and complemented dependent upon information already collected (Merkens 2012, pp. 291f.). The study includes 17 interviews, which reflects the concept of a small sample that is diverse as possible (Flick 2012, p. 165). Because of limitations in time, finances and personnel, I try to balance out the complexity of the researched subject on the one hand and the profoundness on the other, leaning towards focusing on the former (ibid., pp. 167f.). The selection criteria for the study sample are very broad in order to not restrict the width of the results in advance. Individuals are selected considering the new aspects they might add to the qualitative analysis (Merkens 2012, pp. 291f.). I included persons with a positive HIV serostatus that are for at least six month in a successful medical therapy. These are the only inclusion criteria for the study. In addition, epidemiological numbers of PLHIV in Germany are reflected in the study sample, as the majority of interviewees are MSM.

According to Siegfried Lamnek, additional information on the interviewees can add to the interpretation of the content (Lamnek 2010, pp. 357f). Therefore, I listed socio-demographic sample information. The sample includes five women and eleven men, who are between 30 and 65 years old. The dates of the HIV diagnosis and the beginning of the ART vary. Some participants were diagnosed last year while others were diagnosed 20 years ago. There are variations in sexual orientation, e.g. homo-, hetero and bisexual. The socio-demographic composition of the sample includes individuals with various relationship statuses and includes singles as well as individuals in monogamous and open relationships. Among these, HIV concordant and discordant relationships are present. Various origins, educational levels and professions are represented. Eleven participants have a German background while five participants are non-German. One participant has a Swiss background; two participants relocated from the United States to Germany and two participants from Africa; more precisely, Togo and Cameroon.

This is an explorative study and no particular groups are excluded. Although drug use and sex work is present in some of the interviewees' experience, for the composition of the sample I did not bring sex workers and drug users into sharp focus. As this is a qualitative study, which aims to give recommendations in the field of HIV/Aids prevention, I feel that these specific groups would have to be addressed exclusively for the multitude and complexity of their issues.

As Bryman states, while there may not be definite guidelines in qualitative research, which determine sample size, there are many influencing factors, such as time, finances, personnel and methods. After consideration, I temporarily completed the sample with 16 interviews. However, depending on the saturation of the data categories new interviews still could be added (Bryman 2012, p. 18). To test the saturation of the data categories I conducted and eventually included the last interview in July 2014. As it is advised by Flick, I completed the sample after the saturation of inductive categories was achieved (Flick 2012, p. 161).

3.4 Data Collection

For the purpose of data collection, open qualitative interviews with a guideline were conducted. Overall, I used four techniques: brief questionnaire for further biographical information (see Appendix, p. 91), interview guideline (see Appendix, p. 88), digital recorder and postscript for further information on the interview situation (Lamnek 2010, p. 335). In the following I will present the development of the interview guideline, the interview conduction including progress and atmosphere of the interview situation as well as details of the transcription process.

3.4.1 Interview Guidelines

The categories of the interview guideline derive from the literature review and meetings with professionals from DAH as well as research associates. I used three qualitative studies for the development of the deductive guideline categories. Main issues, concerns and questions that are tackled in or derived from previous studies are covered by these themes.

General themes of the interview guideline:

- HIV Diagnosis and Beginning of ART
- Social Environment
- Protective Behavior
- Sexuality
- Medical Support

In a study conducted by Asha Persson in Australia, the complexity of the research subject and its effects on PLHIV in the context of cultural and individual specificities and therefore the relevance of life histories and situations became apparent (Persson 2013, p. 1075f.). It was concluded that infectiousness is not a cohesive experience (ibid., p. 1076). Additionally, an HIV diagnosis was still seen as maintaining the power to generate self-stigmatization (ibid., p. 1068). Consequently, I included the category *HIV Diagnosis and Beginning of ART* in order to develop insight into the personal situation and personality of the interviewee.

Persson's work also suggests that while in the medical field the culturally manifested preoccupations towards HIV infection are gradually decreasing, these ideas still linger on in the general population due to little exposure to the latest developments in HIV science (ibid, pp. 1067f.). In another study, HIV stigma was also vaguely present in serodiscordant couples (Persson 2010, p. 1489). This and the general notion that public communication of the Swiss Statement reduces stigmatization led me to include the category *Social Environment*.

In Daniela Rojas Castro's study of the knowledge about the Swiss Statement, there was an emotional effect apparent as 64 percent of the participants were less afraid of transmitting HIV after being informed about non-infectiousness due to ART (Rojas Castro et al. 2012, p. 1016). Knowledge about the Swiss Statement led to slight changes in sexual and protective behavior considering condom use and communication as 11 percent declared using condoms less, 10 percent using them more and 56 percent found discussing HIV with their sexual partner easier (ibid.). On the other hand, Persson points out an intricate scepticism towards the information given in the Swiss Statement that was observed among participants with one couple committing to condom protected sex after years of unprotected sex, which resulted in two children (Persson 2010, p. 1490). In interviews conducted before the Swiss Statement in 2004 and 2006, participants who were already aware of similar understandings of undetectable virus load and reduced risk relied mostly on alternative risk-reduction strategies when having unprotected sex. However, as Persson comments, the decision to have unprotected sex was rather based on complex emotions, gender dynamics and the need for normality than plain risk calculations (ibid.). Taking these cues from Castro's and Persson's studies, I decided to include the categories *Protective Behavior* and *Sexuality* in my interview guideline.

Finally, Persson states that participants in her qualitative study in Australia were taken aback by the lack of information on this subject by their HIV doctor (ibid.). Additionally, Rojas Castro's study reveals the awareness of the Swiss Statement was 57 percent among PLHIV and only 30 percent of those stated that they found out about it through their physician (Rojas Castro et al. 2012, p. 1016). These indicators led to the inclusion of the category *Medical Support*.

According to Uwe Flick, the questions of the guideline should be verified by certain standards and posed more or less openly, so the interviewee can answer in a free manner. Accordingly, I checked the guideline questions in consideration of why I ask, what I ask, how I phrase the question and when I ask (Flick 2012, pp. 221f.). For example, more intimate questions about the interviewee's sexuality are put midway through the interview after a short phase of acclimatization and not in the beginning. On the other hand, less intimate questions on medical support are rather put at the end of the interview. However, the researcher was free to make a decision on sequence and timing of questions directly in the interview situation, as inflexible presetting of questions can potentially hinder access to the participant's subjective views (ibid., pp. 222f.).

3.4.2 Interview Conduction

After the introduction and the signing of the informed consent (see Appendix, p. 92), I made sure that the interviewees felt free to talk about their experiences, emotions and thoughts on this subject. As it is common in unstructured interviews, I asked the interviewee in the beginning to give their opinion on the researched object freely, elaborately and narratively (Lamnek 2010, p. 310). The interviews then generally started with a question on the positive HIV test results and the beginning of the ART, which functioned as an introduction and gave the interviewees the chance to begin with a concrete incident and open up about their personal story, background and main focus. Speaking pauses were accepted without interruptions. During the interviews I maintained a passive yet stimulating communication style and asked the interviewee repeatedly to continue their narration, while tending to use the same choice of words, thus avoiding leading the interview with regards to content (ibid). As a representative of DAH, I was able to facilitate trust and confidence in the interview situation. I followed a rather narrative approach of interview conduction with less predefined questions and an emphasis on the interviewee's narration while I was actively listening (Hopf 2012, p. 352). I predominantly used the interview guideline to check if all themes are covered in the main part of the interview and to make notes for additional questions. Ultimately, I kept questions at a minimum.

I conducted seven face-to-face interviews at the Akademie Waldschlösschen in Reinhausen near Göttingen. In order to create an appropriately intimate and relaxed environment and since the atmosphere of this seminar was busy and lively, rooms isolated from the workshops of the seminar were used to conduct these interviews.(I rewrote this!) In addition, seminar participants being in a reflective mood was helpful in the conducting of the interviews, as the building is located in a rural woodland scenery, which gave the participants a chance to escape the hassles of everyday life over the course of the seminars.

I conducted further seven face-to-face interviews in Berlin. These interviews also took place in a comfortable and undisturbed location, which was usually the interviewees' home. Only one participant preferred to meet at the DAH office, however a private room was also available there. Finally, I conducted two telephone interviews via Skype in order to record the conversations. I informed these interviewees beforehand on the conditions of the interview and let them decide on a suitable time to call. All face-to-face interviews were digitally recorded**.** At the end of the interview I took biographical data and after the interview made a postscript, immediately writing down my impressions. Information on the atmosphere and on specific situations could be used for interpretation (Lamnek 2010, pp. 357f). Interviews ran between 18:53 and 78:02 minutes. The differences in duration can mainly be attributed to the interviewees' varying willingness to talk or competence in articulation and individual pace and phrasing (Lamnek 2010, p. 323). The process of interviewing was marginally adjusted with practice and accumulating information.

3.4.3 Transcription

Before the actual transcription, I derived a selection of guidelines concerning behavioral characteristics on the interviewees, notation, format, the capability of me as the transcriber as well as the capabilities of possible readers (Kowal et al. 2012, p. 439). Ultimately, all interviews were manually transcribed from the digital recordings using a defined set of basic rules and guidelines. I made sure to keep the interviewees' original intent, meaning and details in the transcript. However, to put the interview in a readable form, I made corrections in grammar and syntax, left out pauses and filler expressions, converted dialects or slurred speech to standard German or English, edited repetitions and discontinued sentences and tended to use simple punctuation (Dresing et al. 2012, pp. 19ff.). For the interviewer I used the abbreviation "I" and for the interviewee the abbreviation "IP" was used. Every question or answer starts with a new paragraph. A blank line follows every paragraph. In order to stay true to the original meaning and expression of the interviewee transcriptions of interviews in English are done with basic linguistic corrections only, as English is not my native language.

For the sake of anonymization, I de-personalized names and places by replacing them with a descriptive term in square brackets and made sure that no conclusion on the identity of the person could be drawn from the transcripts. Hence, every interviewee has an alias, which also makes interpersonal control possible.

Example:

> I think the first people that I told were my friends in [German city]. Some friends and a guy I was dating who was also positive. I think in [German city] it's a bit different than in the rest of the world because there is not much of a stigma about it. I became somehow more comfortable talking about it and being open about it with people. And then it was about two years later that I told my mother and my family and everyone about it. (Robert, 56-61)

The transcribed interviews were saved as Microsoft Word files and titled by number in the sequence of conduction (01-17). A first overview of categories for all transcriptions was completed using Microsoft Excel and further software analysis was completed with MAXQDA.

3.5 Data Analysis

In order to describe the essence of the interviewees' experiences in this study, the hermeneutical phenomenological analysis by Max van Manen was applied, as shown in Figure 3.2 (p. 30). Instead of a detailed practice, van Manen gives recommendations on how to apply phenomenological research. According to van Manen, "the insight into the essence of a phenomenon involves a process of reflectively appropriating, of clarifying, and of making explicit the structure of meaning of the lived experience" (van Manen 1990, p. 77). He advises to approach the phenomenon, which is described in the text, in terms of meaning units or themes and states that in phenomenology themes can be understood as the "structures of experience" (ibid., p. 78). As the researcher, I immersed in the study and varied the data to gain a common understanding of the phenomenon. Freely varying a phenomenon contains looking at the phenomenon from different angles, e.g. its expediency, its history of origins, its nature or its esthetic quality (Lamnek 2010, p. 47). In this process I identified codes and categories in order to make sense of the essential meaning of the phenomenon and to ensure a pure and thorough description of it. According to van Manen, there are three approaches to uncover thematic statements in a text: the holistic, the selective and the detailed approach. The first approach focuses on a sententious phrase that captures the fundamental meaning of a text as a whole. That meaning should then be expressed in such a formulated phrase. The second approach focuses on statements or phrases in the original text that might be most revealing about the phenomenon, which then can be underlined or highlighted. The third approach focuses on revelation about the phenomenon in single sentences or sentence clusters. This is the detailed or line-by-line approach (van Manen 1990, pp. 92f). Examples of significant statements and their related formulated meaning (Figures 4.2, p. 45; 4.4, p. 52; 4.7, p. 63), as well as examples of theme clusters (Figures 4.3, p. 48; 4.5, p. 56; 4.6, p. 59) are included in the presentation of the results.

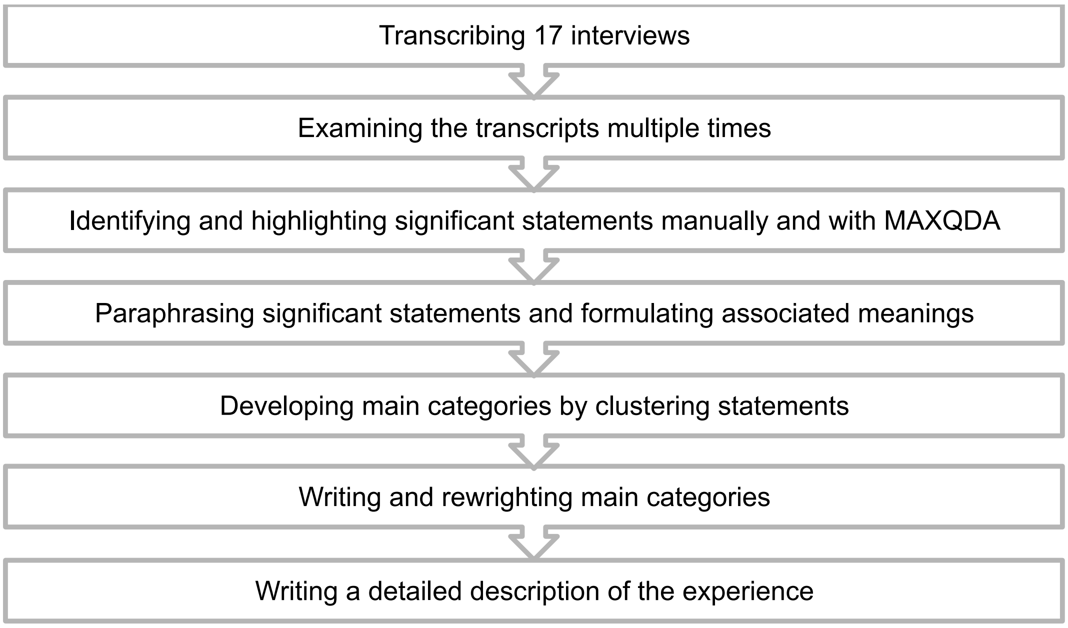


Figure 3.2 Applied Hermeneutic Phenomenological Analysis Process

According to van Manen, the writing process is an essential characteristic of hermeneutic phenomenological research (ibid., p. 7) and the resulting descriptions are at best “compelling and insightful” (ibid., p. 8), as phenomenology ultimately aims to transform “lived experience into a textual expression of its essence” (ibid., p. 36). In the description, the researcher understands and defines the phenomenon. As a guide for reflection four essential dimensions of experience can be helpful: spatiality, corporeality, temporality and communality (ibid., p. 101). The impact of spatiality or lived space is relevant in this study, for example, when participants report on their sexual behavior in dark room bars or cruising parks, but also when non-German participants recount moving to a new country or when participants talk about differences between rural and urban areas or the experience of HIV stigma in their own country. Corporeality is an essential dimension for this study, because this study focuses on the participants’ bodies and their corporeality of being HIV-positive and the status of being non-infectious. The dimension of time is important as well, as the participants talk about subjective time frames and how they experience and perceive time and the passing of time, e.g. time before death, time that passed since the positive HIV-testing, time until the viral load is under a detectable level, or the time it takes to fully accept an HIV identity. Lived human relations are relevant in this study, as the participants got infected with HIV through sexual intercourse. They integrated in the community of PLHIV. They interacted with other people to get information, to get regular check-ups, to get solace and in regard to infectiousness, the participants had to figure out how physically close they could get to others without transmitting the virus. According to Siegfried Lamnek, there is no claim of being exhaustive in the description of a phenomenon, as it is a mere combination of scientifically relevant aspects (Lamnek 2010, p. 51).

3.6 Ethical Considerations

Before the interview, the participants, who signed an informed consent document, were made aware of the aims and methods of the study. The principle of informed consent is a standard to protect the personal rights of the interviewees (Hopf 2012, p. 592). During telephone interviews, informed consent was given on record. In order to prevent any damage or adverse effect for the participants, confidentiality was guaranteed (ibid., pp. 594f.). Therefore, the interviews were anonymized by de-personalizing names and places in the transcriptions and recordings will be deleted after the completion of the study.

3.7 Quality Criteria

The question of how quality assessment in the field of qualitative research can be evaluated is not completely resolved and still needs to be clarified (Flick 2012, p. 487). However, in scientific research quality criteria are essential. Therefore, there are various attempts at examining this question within the field of qualitative research, for example by adapting certain quality criteria from quantitative research or by defining other strategies like triangulation (ibid., p. 485).

According to Creswell, certain standards for the quality of qualitative inquiry should be included and are considered in this study. Thorough data collection procedures were used. The study was embedded in a framework of assumptions and characteristics of the qualitative research approach. Hermeneutic phenomenology, which is a recognized approach to qualitative inquiry, was employed and I gained an understanding for the core idea before I started out with a single focus on ART-induced non-infectiousness. This focus expanded on comparisons, e.g. chronic diseases, or related factors, e.g. HIV stigma or risk behavior, in the progress of the study. Detailed methods were included in the study and multiple levels of abstraction were included in the analyzing process. Finally, I attempted to keep the writing persuasive to give the reader an idea of the experience.

Reflections on the researcher's history, culture and background as well as identification of ethical considerations were also included (Creswell 2013, pp. 53ff.).

In contrast to quality assessment in quantitative inquiry, quality in qualitative research cannot be reduced to universally applicable criteria, standards and/or clearly defined design limits on good or bad use of methodology (Flick 2012, p. 511). However, Creswell formulated eight validation strategies for qualitative studies. He recommends that at least two of the following should be engaged in a study:

- Prolonged engagement and persistent observation
- Triangulation
- Peer review or debriefing
- Negative case analysis
- Clarifying researcher bias
- Member checking
- Rich, thick description
- External audits

In this study three of these strategies are applied: a rich, thick description, a clarification of researcher bias and member checking, as the results were discussed and validated in one-on-one meetings with selected interviewees. New relevant aspects that emerged from these meetings were included in the final description. However, it became clear that the participants rather felt the need to give point to their own perspective on this topic once more, while realizing that overall their perception was already met in the results of this study. According to Flick, standardization of record keeping, e.g. transcription rules, and a reflective approach during the data collection, interpretation and coding process lead to an increase in reliability (ibid., pp. 490ff.). Both are evident in this study. Outlining and defining the steps involved additionally ensures reliability.

3.8 The Role of the Researcher

My previous work in the field of HIV/Aids prevention and advocacy sparked my interest in this project. As a researcher who has knowingly selected his object of research, I informed myself in detail and identified my understandings, beliefs, biases, assumptions, presuppositions and theories and made them explicit to put them deliberately in abeyance during the research process, as the attempt to simply block out and forget might have led to a subliminal manipulation of my reflection (van Manen 1990, p. 47). This way I could isolate the phenomenon and confront the data as purely and openly as possible in spite of what is already known about the phenomenon in general. Moreover, the process of bracketing is a necessary step to transition from the theoretical world, which includes, for example, traditional views, ideological worldviews or scientific understandings, to the natural lifeworld (Lamnek 2010, p. 46). During the research process I attempted to stay critically self-aware, as I did not perceive the act of bracketing out presuppositions as completed in a first step but as an ongoing process. Reflexivity and thoughtful analysis of the research experience and the intersubjective relationship between researcher and participants were maintained. Van Manen refers to this approach as hermeneutic alertness (van Manen 1990, p. 69).

Long before I conducted this research project, I was aware of how of HIV is transmitted, the risks, vulnerable groups and the need for protection. Naturally, in the beginning I still had to learn about it; learn how to be rational about regular testing, how to face uncertainties and basically how to deal with this matter confidently. Since the mid-nineties as a part of my sexual education, I grew up being aware of HIV/Aids. I had friends and acquaintances, who tested HIV-positive, and in the summer of 2011 during a three months internship I worked for the Positive Action Foundation Philippines, Inc. (PAFPI), a nongovernmental Aids aid organization in Manila. All things considered, I was educated about it and, notwithstanding the contact points with PLHIV, my understanding remained rather theoretical. However, the extensive work on this project made me deal with this subject in an unpredictably direct way, which was educational for me, as I could close gaps in my knowledge and meet interesting people that opened up about their personal and often moving stories in the interviews. It was a growing experience that challenged me to reflect upon myself and sharpen my understanding about HIV and the deep impact it has on people’s lives.

4. Results

All together, 17 interviews were used for the data analysis and among these, 816 significant statements were coded. After developing related formulated meanings and finding clusters, the codes were classified into eight main categories that are related to PLHIV's individual experience of non-infectiousness, of which three were compiled in seven subcategories. The categories are presented in a category tree (figure 4.1). Consistent with these specific categories, I will describe what is experienced when the HIV viral load is undetectable and how non-infectiousness after positive HIV testing is individually experienced. Finally, I will give a short comprehensive description, which will illustrate basic insights that proved to be relevant to the experience of non-infectiousness.

Figures of significant statements and related formulated meaning, as well as figures of theme clusters containing associated formulated meanings are included in selected categories (see figures 4.2-4.7).

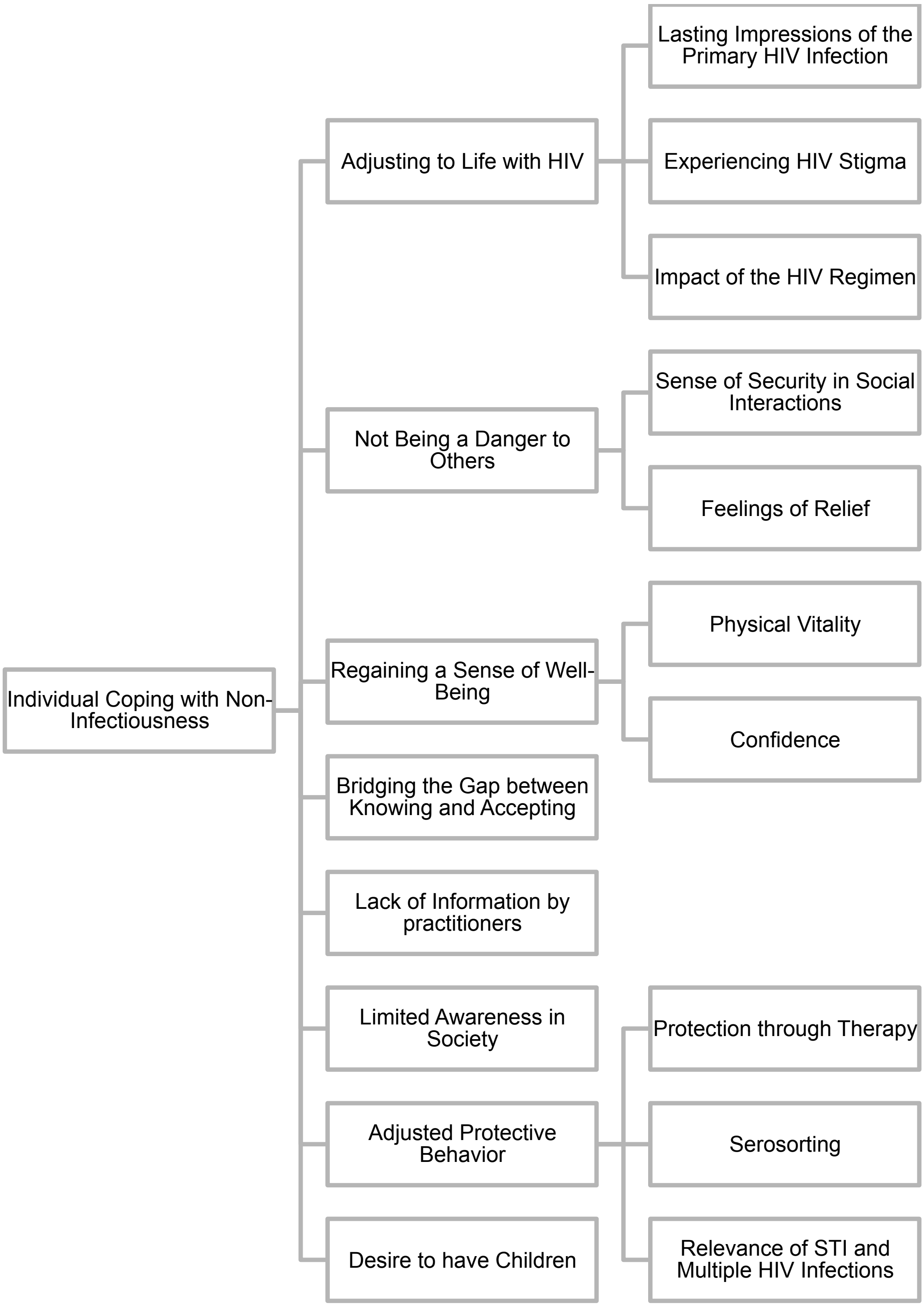


Figure 4.1 Category Tree

4.1 Adjusting to Life with HIV

For all participants, coping and living with HIV was a predominant factor. Notwithstanding the relief over medical and therapeutical improvements, it seemed to be overwhelming to adjust to a life with HIV. Lasting impressions of the primary HIV infection, coping with HIV stigma and dealing with the rigorous HIV regimen, including regular check-ups and strong medication, challenged the participants. Consequently, these domains are represented in the following three subcategories. In the wake of these challenges other aspects seemed to become less significant – including the phenomena of non-infectiousness. Whereas in the introduction of the interviews both aspects, coping with the positive HIV testing and coping with ART-related non-infectiousness were addressed, during the narration of the participants the subject of non-infectiousness seemed to recede into the background. It became apparent that on many levels the HIV infection had an enormous impact on the life of the participants. While the HIV infection was described as a life altering experience, the impact of non-infectiousness on the participants' life appeared to be less radical. The concerns and complaints caused by the HIV infection partially outweighed the participants' experience and awareness of non-infectiousness. Consequently, ART-related non-infectiousness can only be understood in consideration of the individual's living situation, personal history and the subsequent impact of the HIV infection.

4.1.1 Lasting Impressions of the Primary HIV Infection

Acute physical symptoms from the primary HIV infection and subsequent consequences in everyday life, such as sick days at work, produced a lasting impression on participants and it shaped a basic understanding of the HIV infection. Till depicted the exhausting impact of the primary infection as follows:

> Dadurch, dass ich diese Symptome hatte, Durchfall hatte und schlecht geschlafen habe. Ich habe mir teilweise in der Nacht dreimal die Sachen wechseln müssen, mir das T-Shirt wechseln müssen, weil es halt komplett nassgeschwitzt war, den Kopfkissenbezug wechseln müssen. Das sind natürlich Dinge, Erfahrungen, die du im Hinterkopf hast und du denkst dir, wenn ich dagegen nichts mache, das ist für mich absolut nervtötend. Du kannst nicht schlafen und du brauchst ja Schlaf. Das ist das Einzige, wo du wieder ein bisschen Kraft herausziehst und dich für den nächsten Tag vorbereitest und wieder beruhigst. (Till, 106-113)

Participants reported various characteristic symptoms, e.g. unusual and serious colds in summer, pneumonia, remarkably intense pains or memory difficulties: "Kurz vor Therapiebeginn gab es Symptome. Gehirnleistungsfunktionsstörungen. Ich musste anfangen, mir auf der Arbeit Nummern, auch Kurznummern, zu notieren. Kleinigkeiten sind verloren gegangen und ich musste tricksen, um meinen beruflichen Alltag zu bewältigen" (Hannes, 44-48). Robert tried to fight off his HIV infection with post-exposure prophylaxis (PEP), but he stopped taking this medication due to the intensity of his symptoms: “I started taking the pills every single day. After the first week I got really sick and I couldn’t take these pills. It was so miserable. In retrospect I wish I would have kept taking the pills cause maybe it would have made me fight off the infection completely” (Robert, 26-29). Ansgar described severe symptoms, as he was suffering from beastly bone pains, a strong fatigue and warts in his face that only individuals with a weakened immune system can get. The impact of these symptoms was so drastic that he thought about withdrawing from his work as a male nurse, where physical fitness is vital:

> “Bei mir waren es einfach die Symptome. Diese Warzen im Gesicht waren der Horror. Das waren richtige kleine Pinsel, die sich da gebildet haben. Die habe ich dann alle weggelasert bekommen. Ich kann mich noch dran erinnern. Die waren an den Nerven und das war echt nicht schön. Hat man eine abgemacht, hat es geblutet und dann hat es sich immer weiter verbreitet. Das war irgendein Virus halt, der aktiv wird, wenn du immunsupprimiert bist. Als ich die Betäubungsspritze bekommen habe, wurde mir gesagt, jetzt werden sie sich fühlen, wie eine Frau, die eine Botoxspritze bekommt. Das war echt der Horror. Das war nicht das Schlimmste, das war eher ein visuell optisches Problem. Das Problem war, dass ich mit chronischer Müdigkeit und mit Schmerzen reagiert habe. Ich hatte echt Höllenschmerzen.” (Ansgar, 146-156)

While the symptoms of the primary infection provided strong first-hand impressions of frailty, the social interaction with other HIV-positive persons before and after the infection had further influence on the participants. On the one hand, social interaction with PLHIV provided the participants with support, a compound understanding and useful knowledge on HIV/Aids, as Enzo stated concerning his partner and himself: “Es ist ein gewisser Wissensbackground da, weil wir beide ehrenamtlich HIV-Präventionsarbeit gemacht haben. Von daher kannten wir einerseits Positive und das war jetzt auch nichts womit wir uns noch nie auseinandergesetzt hatten, weder mit dem Thema noch mit der Infektion oder dem Positivsein” (Enzo, 24-28). In some cases, these contacts represented reassurance that the participants were not alone or it simply delivered an insight into other HIV positive people’s lives (Till, 559-563; Colin). On the other hand, social contacts with PLHIV especially before the HIV diagnosis sometimes exposed the participants to tragic life stories that shaped the participants view on the disease and their own situation and provoke reflections on frailty and death. Hannes described his experiences with companions who suffered from HIV/Aids before the era of medical HIV therapy, revealing that during the week prior to the interview his last companion from that period died:

> Ich habe vorher einige begleitet, von denen ich wusste, dass sie krank waren, von denen ich wusste, dass mit ihnen experimentiert wurde. Das Thema Blutwäsche, was damals der praktiziert wurde. So als Versuch. Es gab ja keine Medikamente. Dann gab es AZT. Das war ganz schlimm für die Betroffenen. Die Aussichten waren alle nicht sehr rosig. Ich habe aus der Distanz mitbekommen, wie der ein oder andere verstarb. Wenn ich im Nach hinein zurückblicke, alle meine Wegbegleiter aus der Zeit leben nicht mehr. Der Letzte ist letzte Woche gestorben. Der war zu einem frühen Zeitpunkt betroffen. Der letzte Mohikaner ist nun weg. Der ist nicht an den Folgen von AIDS gestorben. Also in der Zeit starben die Menschen schon aus meiner Umgebung. Viele überlebten. Eine große Anzahl konnte nach Vancouver die Dreierkombination genießen. Die waren aber vorgeschädigt aus der Zeit davor. Die sind nie so gesund geworden oder geblieben wie beispielsweise ich. (Hannes, 70-81)

Additionally, stories of problematic medications could evoke fear and also resistance to start ART; for example, potential side effects of HIV medication appeared worrisome to Elmar: “Natürlich hatte ich die Befürchtung, Nebenwirkungen zu haben. Das hatte ich von einigen Freunden mitbekommen, die auch heute noch schon viel länger dabei sind als ich und auch heute noch ganz massive gesundheitliche Probleme haben” (Elmar, 326-328). Enzo described the lasting impression of the tragic fate of companions, which ultimately made him consider himself lucky under his circumstances:

> “Ich habe noch Menschen kennengelernt, die tatsächlich an AIDS gestorben sind. Ich habe über Freunde sozusagen die Generation noch kennengelernt. Nicht eng, aber zumindest kennengelernt. Das hat einem schon geholfen zu sehen, früher sind die Leute daran krepiert. Ich muss einmal am Tag einigermaßen pünktlich eine Pille nehmen. Da kann man sich nicht ernsthaft beschweren. Also das ist dann schon etwas, was einem hilft, zu sagen, ich hatte Glück im Unglück, dass ich jetzt zu dieser Zeit infiziert bin und nicht früher oder zu einem anderen Zeitpunkt. Das ist zwar scheiße, aber obwohl es scheiße ist, habe ich noch Glück gehabt.” (Enzo, 215-223)

A similar feeling of relief is present in Andrew’s remarks, when he referred to acquaintances, who had already have Aids: “Fortunately for me, my body didn’t have to work very hard. I started killing the virus very quickly. So my immune system wasn’t truly compromised like others. I met people that had full blown Aids and they are now undetectable. When you have full blown Aids you no longer have HIV, you’ll have Aids for the rest of your life. You can’t go backwards” (Andrew, 232-237). Andrew confirmed that the encounters and intimate conversations he had with PLHIV provided information, but that it ultimately did not prepare him for what living with HIV is really like, as he did not understand how drastically it would change his life, for example, in regard to his daily routines (cf. Andrew, 40). Poignantly, Robert outlined the shift in perception of HIV over time, which also had an effect on him:

> There are not a lot of people even in my generation who have lost friends. When I was twenty years old in the year 2000 and I went to a bar and saw someone in their thirties who was attractive you know that they lived through the 1980s, knew people and lost people that had died of Aids. I think my generation doesn’t have the same experience with HIV as older guys do. Also it doesn’t seem as daunting as it used to. HIV used to be like a death sentence and I don’t think it’s like that anymore. It is definitely in certain parts of the world but in Europe and in North America, in the industrialized world or whatever, it’s a manageable disease. (Robert, 116-123)

The history of HIV/Aids still had an impact on the participants. This dynamic was evident, for example, when Ansgar talked about his risk calculation and he did not take the latest scientific knowledge on HIV/Aids into account: “Das sind jetzt zweieinhalb Jahre, wo mir das bewusst ist, dass man dann nicht infektiös ist. Aber ich handle trotzdem als wenn ich infektiös ware” (Ansgar, 213-215). The fear of unknown consequences of living with HIV and its potential for stigma and also sexual stigma was manifested in Hagen’s recollection of HIV-positive acquaintances:

> Das war die erste Generation, die durch die Medikamente eben noch dieses typische HIV Gesicht haben, eingefallen, abgemagert, der Blähbauch, dünne Ärmchen, dünne Beinchen, keinen Arsch in der Hose, vom äußeren und vom Leben. Die haben sich alle zugedröhnt, nur auf Droge und nur rumgehurt. Die Sehnsucht war ja da, dass ich nie so werden wollte und natürlich hat mir das Angst gemacht. (Hagen, 203-207)

4.1.2 Experiencing HIV Stigma

Living with HIV includes coping with HIV stigma and internal stigma, which can affect all aspects of everyday life, e.g. employment, healthcare and family. The participants reported several damaging experiences. Damon was rejected care from a dental surgeon (cf. Damon, 233-246). Experiencing humiliation on a personal level, Ingrid mentioned that the biological father of her daughter felt ashamed afterwards having impregnated an HIV-positive person (cf. Ingrid, 82-86). Additionally, Unna described her experience of indiscretion and disclosure at her gynecologist’s in the hospital, where she also worked at:

> Mein Frauenarzt hatte auch gar nichts mit der Materie zu tun. Der war auch leicht überfordert. Da gab es dann auch den Klassiker, dass auf meinem Patientenbogen groß HIV-positiv gelb markiert war, wo ich beim zweiten Mal, wo ich das gesehen habe, darum gebeten habe, das zu entfernen. Das haben die dann auch mit ein bisschen Unverständnis gemacht. Die haben nicht so ganz begriffen, was das dann für mich bedeutet, wenn das auf dem Tresen liegt und jeder im Grunde daran vorbeigeht und das sieht. Dann kann ich mir das auch gleich an die Stirn heften. Das war vor allem auch ein Ort, wo ich gearbeitet habe und wo Klienten von mir Zugang hatten. (Unna, 25-33)

As well as revealing that she stigmatized herself very strongly, e.g. perceiving herself as a “Keimschleuder” (in English: Disease spreader) and “stupid” because she got infected while studying medicine, Anika spoke about the reaction of her mother: “Sie hat sich als Mutter geschämt, dass ihre Tochter das hat“ (Anika, 46). She said that sexuality was a topic that was never discussed at home and described the devastating experience she had with her mother:

> Ich konnte schlecht mit meiner Mutter darüber reden. Dann war das so, du bekommst deine Handtücher, ich bekomme meine. Ich hatte keine Kraft, um zu sagen, spinnst du. Sie hat mir auch gesagt, ich solle es nicht meinen Brüdern erzählen, da sie das wahrscheinlich nicht verkraften würden. Also sie hat ihren Zusammenbruch auf die projiziert.” (Anika, 158-162)

The impact on the individuals' health and well-being can be vast. Falling into depression, Ansgar mentioned that he was not able to look in the mirror without feeling ashamed. This feeling came about due to getting infected during a single time he practiced unprotected sex (cf. Ansgar, 11-17). Robert outlined the damaging effects of stigma and self-stigma, recalling his situation in the United States. He felt silenced and isolated for several years:

> It was mainly because of the stigma. Especially in America there is a huge stigma about it. It's just fear, they are just afraid. First of all, no one will have sex with you. Maybe that's not true, but in your mind that's true. Cause I remember how afraid I was of it when I was 19, 20, 21 and I met somebody and they would tell me that they were positive. It's not that I wouldn't talk to them or hang out with them, but I wasn't going to have sex with them, even if it was with a condom. You know what I mean. And that's kind of fucked up. It's pretty safe. You should assume that everybody is positive and just always have safe sex. There is a stigma and there still is a stigma to it. (Robert, 132-140)

He elaborated on the delicate topic of disclosure and how his experiences informed him:

> HIV is kind of a hard disease to get unless you're getting fucked without a condom. It's not like you are going to get it from a handshake or from a kiss. There is a stigma about it. You worry about who you tell and you also worry about gossip. If someone told me that they were positive or about their health I would never be the kind of person to talk or gossip about that. That is so fucked up and not cool at all. (Robert, 212-217)

After he moved to Germany, Robert experienced fewer stigmas, which personally helped him to be more outgoing about his HIV infection and maintain a healthier attitude:

> I think the first people that I told were my friends in [German city]. Some friends and a guy I was dating who was also positive. I think in [German city] it's a bit different than in the rest of the world because there is not much of a stigma about it. I became somehow more comfortable talking about it and being open about it with people. And then it was about two years later that I told my mother and my family and everyone about it. (Robert, 56-61)

Similar to Robert, Andrew's experiences were less problematic in Germany than in the United States. He complimented peoples' liberal and forthcoming attitude, which was in stark contrast to the ignorance he experienced in his country of origin:

> I felt it more in the States. I feel there's a sexual freedom here that allows a lot of people to not really feel the negative effects that I felt in the states. In the States there is still a lot of HIV stigma. I'm sure it's here too but it's not as drastic. I've had people call me a disease spreader. I would be making out with people and I'm like I need to tell you something before we go on and have them completely pull away saying why didn't you tell me something before we started kissing. It's like, you really think I could give you HIV from my mouth? It's called Wikipedia. Use it! (Andrew, 140-146)

Understandably, addressing stigma can be difficult for PLHIV, e.g. Collin heard his colleague repeatedly talk about HIV-positive people as AIDS victims and even though it aggravated him deeply he shied away from bringing it up (cf. Collin, 23-25). He concluded: "Es ist halt immer das, was man auf die Stirn bekommt: HIV-Positiver. Das klingt am Anfang halt immer so krass" (Collin, 135-137). It became apparent that preconceptions, which derived from the era before 1996, were still present. For example, Unna said she was overwhelmed after the positive testing because, until then, she grew up thinking that HIV was a disease of gays and drug users (cf. Unna, 124-125). Other participants also referred to a dated perception of HIV/Aids. One participant noted, “Dass man damit auch leben und arbeiten und auch alt werden kann, ohne große Beschwerden, das war alles weit weg. Wenn man sich damit halt nicht beschäftigt” (Urs, 42-44). Ansgar described similar sentiments:

> “Das war natürlich erst einmal ein großer Schock. Ich habe dann auch lange Zeit mit einer sehr starken Depression reagiert, wo ich mich auch stark zurückgezogen und wegen der Erkrankung geschämt habe. Alles was dazu gehört. Ich bin ja auch in den Neunzigern aufgewachsen, wo es ja noch keine Medikamente gab. Dementsprechend hatte ich vielleicht auch ein anderes Bild im Kopf als es womöglich die jüngere Generation von heute hat.” (Ansgar, 6-11)

Accordingly, the idea that an HIV infection still coincides with an early death was also present among participants:

> When I first became positive I thought I only had ten years to live. When I had this crazy panic attack in my car that was going through my head, five to ten years, what am I going to do? I have to do as much as I can. I have to really live life, travel everywhere, do all the stuff that I wanted to do. I didn’t think I was going to be around or live longer. (Robert, 125-128)

4.1.3 Impact of the HIV Regimen

One aspect that was central in the participants’ narrative was the HIV regimen, which includes regular check-ups every three months, blood testing and continuous medication at least once a day, thereby requiring a level of discipline and structure. For some participants the HIV regimen led to physical, emotional or simply logistical complications: “Das fand ich sehr schwierig, die Vermischung von Persönlich-Privatem und Job. Das war auch logistisch schwierig. Aufs Klo gehen, Tabletten einnehmen, vorher noch etwas essen. Das hat mir nicht gefallen, dass das in mein Berufsleben hineingetragen wird.” (Enzo, 178-181). Essential adjustments and changes in life style added to the pressure that lies on PLHIV in everyday life, e.g. considering diet, physical condition and traveling habits. Andrew described the broad impact of his HIV regimen:

> I didn’t realize that you basically have to look at every little thing that you do in a different way. When I travel, I have to make sure that I have enough medication. I have to make sure that I can legally bring that medication into the country that I want to go to. I have to make sure that I eat properly, get enough sleep and don’t drink or smoke too much or party too hard. Because if you do that you’re gonna weaken your immune system even further, and having an already weakened immune system, that’s not good. (Andrew, 41-47)

Ultimately, it took him by surprise how drastically his life changed due to having to take medication that would last for the rest of his life:

> "Whenever I get sick, I'm no longer a person who gets sick a day or two. My day or two has become a week or two. Why am I feeling tired today? Oh it's because I haven't eaten enough. Where as before, living in [city in the U.S.] and everything is go, go, go, I always had energy. I didn't really have to think about what I was eating. It was always like, I'll get something later. And now, when they call HIV treatment a regimen they are not kidding. I have to make sure that I eat a proper amount throughout the whole day and I have to make sure it's around the same time and I have to take my medication around the same time, daily. You have a three hour window. I have reminders constantly." (Andrew, 237-245)

After testing positive, the beginning of ART is often perceived as a second turning point, as it is the beginning of a presumably lifelong therapy. For Unna it made the infection official and turned it into something that required counter-action in the form of medicine. She started ART during her pregnancy and she knew there was no alternative (cf. Unna, 79-87). Moreover, medical therapy bears the risk of side effects, e.g. depression or suicidal tendencies. Some participants talked about their depression getting worse due to their infection: "Am Anfang in meiner Depression habe ich mich auf dem Sterbebett gesehen. Das war echt heftig damals. Ich bin eh schon so ein grunddepressiver Typ. Das hat das alles noch verstärkt, wie das dann in einer Depression ist. Mangelndes Selbstwertgefühl. Ich habe echt gedacht ich muss sterben" (Ansgar, 47-50). Andrew suffered from similar symptoms, which resulted in a change in medication:

> "And not to mention I had to change my medication, because the tripler, a year after taking it, started making me depressed and I've always been a very optimistic person. So it's like, when I start thinking, oh I could just jump of my balcony, that's clearly not me. So I went to the doctor and she immediately changed the medication and she said, stop taking them now. After a few months everything went back to normal and now I'm not having random suicidal thoughts. Luckily I have a good sense when something's up, why am I crying, why am I not going home until four in the morning because I decided to go for a long walk, fell asleep on a bridge somewhere. Really random shit! And it's not because I had a beer. A beer won't make me do that and clearly something else is happening." (Andrew, 209-219)

Some participants had to undergo several changes in medication, as Nicola stated: "Ich habe starke Beschwerden in den Füßen gehabt, immer wieder dieses Stechen in den Füßen. Irgendwann Kälte, Taubheit. Dann haben sie Neuropathie diagnostiziert und dafür bin ich dann auch behandelt worden. Dann hatte ich das Gefühl, ich wollte nur noch schlafen. Ich bin halt mehrere Male umgestellt worden" (Nicola, 11-14). The daily medication was often perceived as a constant reminder of the infection. Especially in the beginning of ART, it seemed difficult for some participants to figure out an appropriate regimen. Till described his struggles getting used to the routine:

> Am Anfang habe ich mir dann gedacht, fuck, das wird jetzt immer so sein. Insbesondere, weil du ja auch darauf achten musst. Du musst die ja jeden Tag nehmen. Du musst ja auch deine Disziplin da reinkriegen. Mir fiel das dann teilweise auch sehr schwer, wenn ich das Haus verlassen habe, fiel mir danach noch ein, Mensch, du musst ja dein Medikament noch mitnehmen, weil ich weiß, ich bin am Abend vielleicht nicht zuhause, habe aber nur ein vierstündiges Zeitfenster. Also ich persönlich nehme meine Medikamente immer abends zwischen sieben und acht Uhr. Wenn ich weiß ich bin abends um zehn oder um neun Uhr wieder zu Hause, dann nehme ich sie nicht mit, weil ich weiß, ich habe ein Zeitfenster von drei oder vier Stunden, da kann ich variabel sein, das ist okay. Wenn ich aber weiß, ich gehe jetzt aus oder wie heute Abend, ich gehe jetzt arbeiten, dann nehme ich meine Medikamente mit und dann denke ich mir nicht viel dabei. (Till, 706-717)

Ansgar reported problems that occurred due to the medical routine: “Dann kommen so Momente, wo man nicht weiß, hast du sie jetzt genommen oder nicht. Weil das auch so im Alltag drin ist” (Ansgar, 36-37). His biggest concerns were his gastro-intestinal problems, a loss of appetite and diarrhea that kept him from gaining weight and made him wish for a cure so he would not have to take his medication anymore: “Ich habe natürlich auch die stille Hoffnung, dass es irgendwann heilbar ist, damit ich nicht mehr diese Mordsmedikamente nehmen muss“ (Ansgar, 45-47). Another worrisome aspect that was mentioned by participants is the long-term effect of medication; for example Andrew was well aware of this subject: “They are just starting to realize how hard treatments are affecting people that are on them for twenty, thirty years. And it does not look promising for me. I am more likely to have early-onset dementia. I am more likely to be highly susceptible to rare cancers” (Andrew, 206-209). Ultimately, it is the medication that makes him feel toxic to himself more so than feeling toxic to others, as he stated: “I’m basically a walking chemo factory. I constantly have medicine coursing through my veins. All the time!” (Andrew). He elaborated on the ongoing pressure:

> “Yes sweetheart, it’s a big problem! Not to get super personal, but one of the main things it does to me and annoys me, I haven’t had a proper normal shit since taking medication. Two years without having that one thing of normalcy. It starts to fuck with you after a while. I eat healthy all the time, yet it’s like, really? I have daily reminders, like that pillbox next to the dining table. I have reminders all the time. You are living with this.” (Andrew, 227-232)

Alternatively, Enzo described how he could channel his aggressive feelings towards his infection by starting an aggressive medical therapy:

> Die ART ist eine Möglichkeit gewesen, dagegen anzugehen. Weil das halt eine aggressive Pharmatherapie ist und mir war nach einer aggressiven Therapieform. Das war für mich eine gute Art zu reagieren. Ich gebe mir jetzt eine chemische Keule. Ich will, dass etwas Heftiges passiert. Ich nehme jetzt die Dinger und die Nebenwirkungen waren mir relativ egal. Ich hatte das dringende Bedürfnis, dieser Aggression in irgendeine Form der Aktion umzusetzen und sei es eben nur dass ich Pillen schlucke, weil viel mehr kann man ja auch nicht machen. (Enzo, 106-113)

In spite of all this, the participants emphasized the importance of maintaining a life-affirming attitude, which goes hand in hand with successful medical therapy. Elmar started medical therapy after years of waiting until he got severely sick on a summer vacation. In this situation therapy seemed to be a relief. About his outlook in life he stated: "Was ich wichtiger finde, das ist die neue Möglichkeit, die neue Situation, die sich durch die Therapie ergibt. Das ist etwas, dass ich interessant finde und produktiv und was mein Leben verändert. Dieses Nachhängen, wie ist es passiert und wer hat daran Schuld, das ist ja nicht einmal von akademischen Interesse" (Elmar, 226-230).

4.2 Not Being a Danger to Others

When the impact of an undetectable viral load was addressed, most participants put an emphasis on the significance of not being a danger to others. The information about the effects of a reduced viral load was individually understood and accepted by participants in different ways, different contexts and paces. Eventually, the sentiment of not being a danger to others led to a sense of security in social interaction as well as evoking feelings of relief. Accordingly, these two responses constitute two subcategories.

Selected Examples of Significant Statements and Related Formulated Meanings	
In meiner Sexualität eigentlich nicht. Ich habe mich nicht gefährlich gefühlt. Aber als es darum ging das Kondom wegzulassen, da war es anscheinend da. Wie soll ich es sagen? Ich glaube, das Gefühl wurde mir erst klar als ich die Erleichterung wahrgenommen habe. Wenn die Erleichterung so groß ist, dann muss die Angst vorher auch groß gewesen sein. (Ingrid, 112-116)	Undetectable viral load reduces the subconcious burden of being infectious
Und jetzt ist es nochmal sicherer und zumutbar, dass man da erwartet, dass mit einem umgegangen wird. Ich hatte keine Beziehung. Ich wollte nicht. Ich konnte mir das nicht vorstellen. Und als ich dann unter der Nachweisgrenze war, war das ein Risiko, mit dem ich umgehen kann. (Anika, 139-142)	Reduced risk of HIV transmission leads to an increased feeling of security and self-esteem

Figure 4.2 Related Formulated Meanings: Not Being a Danger to Others

4.2.1 Sense of Security in Social Interactions

When participants talked about non-infectiousness, they declared that having an undetectable viral load either resulted in a feeling of relief or a sense of security, which both contributed to a reduced internal stigma. However, in some interviews the participants were asked to take up a stance on this subject, as it was not covered in the initial narration. In some interviews the reaction seemed to be slightly ambivalent, as if the participants still had to figure it out or reassure themselves considering what exactly they feel about it, e.g. when Robert merely presumed: “It makes me feel good to have a viral load that is not detectable I guess” (Robert, 175). In other situations the reaction was straightforward: “Dann war ich unter der Nachweisgrenze und ja, das fühlt sich cool an, dieses Gefühl nicht mehr infektiös zu sein” (Anika, 137-138). Before this statement, Anika described how she suffered from being infectious and from being a risk for others, especially in her profession as a doctor: “Das schlimmste war das Gefühl, es ist irgendwie nicht nur mein Problem. Ich hab mir alles gewünscht, aber nicht ansteckend zu sein und nicht in einem Job zu sein, wo ich in einen Konflikt gerate“ (Anika, 68-70). She feared potential career restriction because of the danger of infectiousness and she was aware that being infectious has an impact not only on the individual, but rather on the whole social environment. Anika addressed foremost internal stigma and the fear of social alienation, but due to her undetectable viral load she found a renewed sense of confidence, demanding confrontation instead of avoiding it. The increase in self-assurance generally allowed her to cope with stressful situations more constructively: “Und jetzt ist es nochmal sicherer und zumutbar, dass man da erwartet, dass mit einem umgegangen wird. Ich hatte keine Beziehung. Ich wollte nicht. Ich konnte mir das nicht vorstellen. Und als ich dann unter der Nachweisgrenze war, war das ein Risiko, mit dem ich umgehen kann” (Anika, 139-142). Andrew described a similar notion, while taking into account the danger that the HIV drug treatment could mean for him. Partially his motivation for starting ART was altruistic. He wished to minimize the danger for others: “If anything, part of me taking medication was to protect others. I couldn’t care less about what HIV does to me. I’m more concerned about me infecting others. I want it to stop with me, because the life that I have now I don’t want anyone else to have, especially not because of me” (Andrew, 220-223). Furthermore, Andrew argues that, while it makes logical sense to talk about an undetectable viral load, he felt that the term non-infectious would be better. He elaborated on having an undetectable viral load:

> The first time that I got into contact with someone who was undetectable I was wondering how is that even possible? I didn’t understand. You always have it in your blood, so just because you can’t detect it doesn’t mean it’s not here. Technically you will always be detectable. They can’t detect the virus in your blood but they can detect the antibodies. I personally would always test positive. They don’t necessarily test for the virus. They test for the antibodies. You have to have more intense testing in order to find the virus. (Andrew, 81-88)

The feeling of security and self-confidence also turned out to be relevant in sexual interaction. Damon pointed out that it became easier for him to interact with HIV-negative sexual partners, because he felt less self-conscious about his HIV-positive serostatus: “Ich fühle mich deutlich selbstsicherer, gerade in Gesprächen. Insbesondere mit potentiellen HIV-negativen Sexualpartnern. Es hat den Makel für mich emotional reduziert" (Damon, 108-110). He reported that after he ignored his status for a year, during which he omitted doctor's visits as well as any sexual activity, he finally faced his situation with the aim of being non-infectious: "Nach einem Jahr war ich an dem Punkt, wo ich dachte, es hilft ja alles nichts, ich möchte nicht ansteckend sein, ich fange eine Therapie an und gucke, wie ich das ärztlich löse" (Damon, 63-66). After some hesitation and an intense conversation on personal issues, Robert admitted that the awareness of a reduced viral load improved his sense of security, which is present in his sex life: "But yes, having zero viral load feels good. It feels like it's rare, it would be very difficult to pass it on to someone else" (Robert, 179-180).

4.2.2 Feelings of Relief

Some participants voiced an ambivalent feeling of relief. Besides the aforementioned reprieve from being seen as a carrier of an infectious disease, there was also a somewhat cathartic feeling and a reprieve from fearing HIV transmission from others. Collin stated: "Das klingt jetzt ganz komisch, aber irgendwie war es auch eine Erleichterung. Weil man immer denkt, da ist etwas und man könnte das erwischen und jetzt ist es wie es ist und man braucht sich darüber keine Gedanken mehr zu machen" (Collin, 127-129). Similarly, Enzo claimed to be a bit more carefree: "Irgendwas Gutes muss das ja auch haben und sei es nur, dass ich keine Angst mehr habe vor einer Infektion" (Enzo, 276-277). He elaborated on this carefree feeling and the loss of fear, which was a constant part of his sexual behavior before: "Befreiend. Es ist ein bisschen schizophren. Eine schizophrene Situation. Aber bei dem ganzen Stress, den man hat, fällt dieser Stress, die Sorge, sich beim Sex mit HIV zu infizieren, von einem ab" (Enzo, 316-319). Other participants hinted at the pressure that they felt before: "Die Information aus dieser Studie, dass ich nicht mehr ansteckend bin, war ein richtiger Befreiungsmoment. Da konnte ich richtig durchatmen" (Hannes, 96-98). Ingrid described a blessing in disguise:

> In meiner Sexualität eigentlich nicht. Ich habe mich nicht gefährlich gefühlt. Aber als es darum ging das Kondom wegzulassen, da war es anscheinend da. Wie soll ich es sagen? Ich glaube, das Gefühl wurde mir erst klar als ich die Erleichterung wahrgenommen habe. Wenn die Erleichterung so groß ist, dann muss die Angst vorher auch groß gewesen sein. (Ingrid, 112-116)

Reflecting on the meaning of non-infectiousness, Collin emphasized his emotional relief and the possibility of connecting with a partner sexually without barriers:

> Freiheit. Weil so oder so, gerade auch wenn man in einer Partnerschaft ist und verliebt ist. Da kann ich mir nicht vorstellen, die ganze Zeit mit Kondomen Sex zu haben. Da würde wirklich etwas fehlen. Da will ich meinen Partner wirklich ganz spüren. Mit allem, was dazu gehört. Insofern bedeutet das, eine wiedergefundene Freiheit. (Collin, 149-153)

4.3 Regaining a Sense of Well-Being

An undetectable viral load was rationallised by some participants as a synonym for being healthy, receiving a successful therapy and for not being completely at the mercy of an infection that made them feel physically frail at times and that is intellectually charged with a daunting history. Ultimately, the contrast of coping with an infection and adjusting to an intense therapeutical array on the one side and bristling with physical strength on the other seemed irritating to some participants. The overall reaction, however, was encouragement. The subject of regaining a sense of well-being could be divided into the two subcategories, namely physical vitality and confidence.

Example of a Theme Cluster with Associated Formulated Meanings	
Regaining a sense of well-being	**Vitality** Physical fitness Absence of pain or frailty Normality Quality of life Strong immune system Holistic health **Confidence** Feeling of self-worth Confidence in success of ART Motivation Emotional and mental health Confidence in the future Gratefulness

Figure 4.3 Theme Cluster: Regaining a Sense of Well-Being

4.3.1 Physical Vitality

For several interviewees having an undetectable viral load was synonymous with good health rather than non-infectiousness, e.g. Collin emphasized an absence of frailty:

> Nicht wirklich krank zu sein. […] Nicht Sklave seiner selbst zu sein oder Sklave einer Krankheit, dass irgendjemand oder irgendetwas einem diktiert, wie man zu leben hat oder an was man sich halten muss. Klar man muss halt jeden Tag seine Tabletten nehmen und man weiß nie was kommt oder ob sie noch wirken und das kann je nachdem doch ganz schnell gehen, aber so far so good. (Collin, 149-157)

In this context, Ansgar said: "Schon nach sechs Wochen war ich unter der Nachweisgrenze. Es hat mir auch die Angst genommen, dass ich mit der nächsten Erkältung eine Lungenentzündung bekomme und sterbe" (Ansgar, 185-187). Notwithstanding minor side effects, Hagen felt physically fit and he highlighted the boost in security he gained from taking his medication and having an undetectable viral load: “Sehr schnell war ich unter der Nachweisgrenze. Körperlich habe ich mich eigentlich ganz normal gefühlt. Ich hatte natürlich ein paar Nebenwirkungen durch die Medikamente gehabt, aber es hat mich sicherer gemacht. Ich tue jetzt alles, was mir möglich ist, um gesund zu bleiben. Ich fühlte mich ja trotz dieser Viruslast nicht krank” (Hagen, 311-315). Participants described this sentiment with remarks like “Ich fühle mich besser in meiner Haut. Das Gefühl zu haben, ich bin praktisch nicht infektiös” (Anika, 212-213), “Das hat sich mit Therapiebeginn schlagartig geändert. Da war dann das alte Leistungspotential wieder vorhanden” (Hannes, 48-49) or simply “Ich fühle mich mit dieser Information gut” (Alex, 68). Beginning medical therapy represented a promise for a healthier life: “Ich habe mich darauf gefreut, dass ich endlich meine Therapie beginnen kann. Ich habe mich auch darauf gefreut gesünder und nicht mehr ansteckend zu sein” (Damon, 99-100). Participants who struggled a lot from symptoms of the primary infection put an emphasis especially on good health:

> Ich hatte dann die Schmerzen nicht mehr, die sind nach ungefähr vier Wochen weggegangen. Die Viruslast ist unter die Nachweisgrenze gefallen. Dann die Probleme mit dem Schlafen, welche ich zuerst nicht auf die Medikamente zurückgeführt habe. Ich bin ja auch ein Typ der immer mit sich selbst beschäftigt ist und immer irgendein Problem hat. Ich habe erst einmal gut damit gelebt. Die Symptome sind zurückgegangen und ich habe meinen Alltag wieder hingekriegt. Ich konnte auf einmal wieder über berufliche Veränderungen nachdenken und so. Die Beziehung ist besser gelaufen. Ich habe mich sehr wohl damit gefühlt und sicher. Ich wusste halt auch, dass ich durch die Therapie das Rentenalter erreichen kann. Es hat mir ein großes Sicherheitsgefühl gegeben. (Ansgar, 176-185)

Some participants underwent a subtle recovering of the immune system when medical therapy started. Unna stated that her quality of life increased according to the improvement of her immune system (cf. Unna, 87-88). Collin elaborated on the subtle changes:

> Man weiß, dass es da ist, aber es ist schon komisch. Man spürt ja überhaupt nichts. Sogar nachdem ich mit den Tabletten angefangen habe, habe ich mich körperlich gleich viel besser gefühlt. So Kleinigkeiten, dass, wenn man eine Wunde hat, die nicht sogleich verheilt oder Zahnfleischbluten oder Fußpilz. Wo gleich alles wegging, weil man spürt, dass der Körper sich wieder wehren kann (Collin, 35-40).

Elmar reflected on the decline of his immune system before therapy and his blossoming well-being when he began it after delaying it for several years: “Das ist für mich eine 180 Grad Wendung in meinem Gesundheitsleben und es ist ganz erstaunlich festzustellen. Die Kräfte, die vorher so nach und nach verschwunden sind – Abwehrkräfte nimmt man ja nicht unbedingt aktiv wahr – aber wenn die dann zurückkommen das merkt man dann doch” (Elmar, 67-70). Furthermore, he pointed out the overall positive effect of his revived sexual life, which added to his overall health:

> Es ergänzt einen, nicht nur sexuell. Das wirkt sich im gesamten System aus. Man hat ein ganz neues Gefühl zu sich selbst oder mit sich selbst. Das ist eine Sache, die ich im Moment noch sehr genieße. Vielleicht, weil es noch relativ neu ist, aber vielleicht hält es ja auch noch länger an. Keine Ahnung. Das ist etwas, wo ich viel Spaß dran habe, viel auszuprobieren und ich mich selbst in meinem Alter recht jung fühle und unbedarft. (Elmar, 92-98)

During some interviews it was apparent that laboratory values became increasingly relevant for the participants, as the viral load level reflects the health status and the level of infectiousness. Urs emphasized the positive reaction of his doctor: “Dazu sagt er immer, das sind Traumwerte. Ich merke auch nichts. Ich bin nicht müde. Ich bin nicht schlapp. Ich habe wieder meine Energie wie vorher. Ich habe mich erholt” (Urs, 69-71). Enzo emphasized the importance of laboratory values and described the psychological effect of reduced numbers:

> Wichtig fand ich, dass sich die Werte gebessert haben. Das war ein konkretes Ergebnis. Eine psychologische Geschichte auch. Das ist eine ganz wichtige Sache. Ich hatte kaum Nebenwirkungen. Eine gute Verträglichkeit. Keine große körperliche Unannehmlichkeit. Das war eher positiv, weil die Werte gesunken sind. Man hat das Gefühl, die Infektion ist behandelbar, es passiert etwas. Nach einem negativen Ergebnis, kam dann eben auch ein positives Ergebnis. Das hilft, den Status zu akzeptieren. (Enzo, 144-150)

4.3.2 Confidence

Several participants pointed out that the more information they got about the current scientific state on HIV/Aids, the more they gained a feeling of self-worth and confidence in the wake of their own infection: “Mit meiner Infektion habe ich dann erfahren, dass es mittlerweile ganz andere Therapiearten gibt. Mir hat es ein großes Sicherheitsgefühl gegeben. Das tut es auch immer noch” (Ansgar, 190-193). The posive effect of an undetectable viral load on self-esteem and a regained feeling of self-worth were perceived as essential: “Ich finde halt, die Diskussion der Nichtinfektiösität ist ein ganz wichtiges Thema. Ich weiß, bei vielen von uns, für viele Positive nagt HIV am Selbstwertgefühl. Deswegen finde ich es total wichtig, dass die Leute das wissen.” (Nicola, 78-81) For some participants the reduction of the viral load counteracted the feeling of helplessness that overcame them with the diagnosis and the inexplicability of the pathway of HIV transmission. The feeling of being able to take action increased confidence in the therapy and in the future: “Aber das macht es definitiv noch mal einfacher. Auch das Gefühl, ich kann was machen. Ich laufe nicht damit rum und es gerät außer Kontrolle. Das hilft total” (Anika, 230-232). In this context, undergoing a potent treatment and therefore being capable to fight the infection takes center stage. It is understood that the HIV regimen is the basis for good health as well as non-infectiousness. Additionally, the importance of coping with the infection and the impact of medical treatment on a rational rather than a mere physical level were emphasized:

> Das gute an einer ART ist, man ist beschäftigt, man bespricht die Medikamente, die Vor- und Nachteile, man hat das Gefühl, dass man die Dinge wieder in die Hand nimmt. Neben all den medizinischen Komponenten war das ganz wichtig. Man fühlt sich nicht mehr so ausgeliefert. Man hat etwas, womit man sich intellektuell und wissensmäßig konkret auseinandersetzen kann, auch um es zu bewältigen. (Enzo, 122-126)

Enzo expounded on the uplifting psychological effect of ART:

> Abgesehen von allen Gründen die dafür oder dagegen sprechen, war es für mich eine ganz wichtige psychologische Komponente, sofort damit anzufangen, weil ich so das Gefühl hatte, wenn ich mit der ART anfange, dann habe ich etwas, was ich gegen diese Infektion tun kann. Ich habe den Drang damit umzugehen, es anzugehen. Das hat das Gefühl der Hilflosigkeit, völlig überraschend und aus heiterem Himmel mit dieser Infektion konfrontiert zu sein, abgemildert. Jetzt ist das so passiert, aber jetzt kann ich wenigstens etwas dagegen tun. Ich habe das Gefühl ich mache etwas, ich nehme das Heft wieder in die Hand. Von diesem „es überkommt mich“, dieser Passivität, zu eine aktiveren Rolle zu kommen, etwas aktiv machen zu können. (Enzo, 68-77)

Collin expressed confidence in his situation: “Man steht dazu und ja, okay, man muss halt diese blöden Tabletten jeden Tag nehmen, die natürlich auch nicht so gut für den Körper sind, aber da bin ich auch zuversichtlich” (Collin, 129-132). He kept a life-affirming attitude and mused about potential medical improvements, e.g. depot injections: “Man arbeitet ja auch daran, dass als nächstes irgendwie eine Spritze kommen wird, die man jedes Quartal bekommt. Ich glaube, da ist man auf einem guten Weg. Ob man jetzt die Generation ist, wo man das komplett weg bekommt und heilen kann, das steht in den Sternen, aber ich glaub, man kann ganz gut so leben” (Collin, 132- 135). Jokingly, Robert stated that having an undetectable viral load sometimes made him think that he could opt out of medication: “It makes me feel like, ok maybe I don’t even have to take it and I can just wait” (Robert, 175-176). Ingrid reflected on her confidence in the success of ART and her future outlook:

> Eine einzige Relevanz hatte es und das sind die Kitschmomente. Dass ich das noch erleben darf, dass das Kind eingeschult wird und ich dachte, ich werde mit 30 sterben. Aber auch das gibt langsam nach. Es geht nicht darum es zu diminuieren. Es hat sich einfach so ergeben. Die Gefahr bei mir im Dorf unters Auto zu kommen ist doch viel größer. Es hat sich total relativiert. Es gibt ganz kleine Momente und das kann ich auch gerne zugeben, wo das lange Überleben nicht heißt, ach cool, jetzt kann ich ja viel länger, sondern, jetzt habe ich schon vier Jahre verbraucht. (Ingrid, 129-135)

4.4 Bridging the Gap between Knowing and Accepting

The participants made the distinction between staying rational and being emotional. Accepting a non-infectious HIV corporeality was experienced as a progression over time that for some took years to comprehend. It seemed difficult for the participants to instantly accept what they came to know about non-infectiousness. The differentiation was made several times using expressions like “etwas zu wissen und es wirklich zu leben” (Ansgar, 52-53) or “es gibt zwei Ebenen, die eigenen Emotionen und den Kopf” (Nicola, 66). To varying degrees, coping with HIV related non-infectiousness was perceived as a time-consuming progress. To describe this progression, key phrases were used, e.g. “schleichender Prozess”, “nur langsam”, “erst ein halbes Jahr später”, “viele Jahre”, “erst”, “es hat viel Zeit gebraucht”, “erst mit der Zeit”.

Selected Examples of Significant Statements and Related Formulated Meanings	
Ich wusste vor der Veröffentlichung der EKAF [Eidgenössische Kommission für Aids-Fragen] schon, dass man sich bei einer verringerten oder nicht nachweisbaren Viruslast nicht anstecken kann. Also wenn man keine andere sexuell übertragbare Krankheit hat. Aber im Selbstbewusstsein hat es sich nur langsam niedergelassen. (Nicola, 21-24)	Accepting non-infectiousness on an individual level takes time and is based on more than sheer knowledge
Es gibt ja die zwei Ebenen, die eigenen Emotionen und den Kopf. Im Kopf habe ich alles gemacht was man machen kann und das andere stand nicht zur Debatte. (Nicola, 66-67)	Making the distinction between rationality and emotionality in thought and in action

Figure 4.4 Related Formulated Meanings: Bridging the Gap between Knowing and Accepting

Refering to the process of understanding that the course of an HIV infection has become comparable to that of a chronic disease, Robert said: “It has taken me the last five or eight years to come to that realization” (Robert, 123-124). Coping with HIV-related non-infectiousness was always put within the conext of coping with the infection itself, as Urs stated: “Das ist ein Prozess der in einem abläuft. Also ich kann nicht heute die Diagnose bekommen und morgen in die Welt hinausposaunen, also Leute, so ist es” (Urs, 111-113). This internal process can last even when external circumstaces are beneficial. While her husband allegedly assured Unna that he had no problem with her positive HIV status and they practice HIV-serodiscordant sex without condoms, she admitted that she continuously struggled with her infection: “Was auch immer wieder Thema ist, nicht aufgrund von Infektiösität oder der Angst anzustecken, sondern weil ich das mit mir selber ausmachen muss. Es ist wirklich so, dass ich weiß, mein Mann hat eigentlich keine Schwierigkeiten mit meinem HIV-Status. Für ihn ist das ein geringeres Problem als für mich, die positiv ist.” (Unna, 111-115). Ansgar described the resistance to accept and the disconnect created by knowing something rationally and accepting it emotionally as follows:

> Ich habe das erst mit der Zeit begriffen. Ich habe eigentlich von Anfang an gewusst, dass ich damit bis zur Rente leben kann, weil mir das meine Ärztin auch gesagt hat. Aber etwas zu wissen und es wirklich zu leben und wirklich zu begreifen, dass man damit gut leben kann und dass es kein Schandmal ist, das sind zwei verschiedene Dinge. Das hat eine Zeit gebraucht. (Ansgar, 50-55)

Another aspect of this progression is the necessity to reassess manifested attitudes. Living in a serodiscordant relationship without being on HIV medication, Ansgar got used to relying on other protective methods, resulting in a reluctance to inform himself: “Diese Nichtinfektiösität kam dann ja erst mit der Therapie. Da waren wir ein Jahr zusammen. Diese Nichtinfektiösität hat für mich im Kopf nie existiert. Für mich war immer klar, ich muss ihn schützen” (Ansgar, 201-203). Being in a relationship can insulate HIV-positve people and make it harder to grasp new developments and their far-reaching implications. Nicola remembered that she did not realize the importance and the impact this could have on a public level, when she first dealt with non-infectiousness within the confines of her marriage: “Ich weiß, dass ich in der Diskussion immer gesagt habe, wofür brauchen wir Studien, das wissen wir doch. Aber zu dem Zeitpunkt war ich ja noch mit meinem Mann zusammen. Da habe ich noch nicht realisiert, was es mir ermöglicht, oder dass ich will, dass jeder es weiß. Das war halt vorher. Um 2006 herum habe ich davon erfahren” (Nicola, 154-158). She elaborated on the possible relief this could cause for HIV-positive persons:

> Ich finde die ganze Sache schwierig, weil ich schon länger an Depressionen leide. Schon vor HIV. Und ich bin auch in Behandlung. Also HIV kann das noch verstärken. Ich glaube, dass es vielen so geht. Und ich glaube, dass viele davon profitieren können, wenn die Allgemeinbevölkerung weiß, was die Nichtinfektiösität bedeutet. Ich bin mir sicher, dass es nicht nur mir so geht. (Nicola, 159-162)

Recalling her living situation, Nicola explained the difficulties in bridging the gap between knowing and accepting: “Es gibt ja die zwei Ebenen, die eigenen Emotionen und den Kopf. Im Kopf habe ich alles gemacht was man machen kann und das andere stand nicht zur Debatte, dadurch, dass ich in der Beziehung war und mich ja für die Beziehung entschieden habe” (Nicola, 66-69). Ultimately, she described her progress in truly accepting non-infectiousness over the years:

> Ich wusste vor der Veröffentlichung der EKAF schon, dass man sich bei einer verringerten oder nicht nachweisbaren Viruslast nicht anstecken kann. Also wenn man keine andere sexuell übertragbare Krankheit hat. Aber im Selbstbewusstsein hat es sich nur langsam niedergelassen, dass ich auch das Gefühl habe, okay, wenn ich meine Pillen richtig nehme und die funktionieren, dann bin ich auch nicht ansteckend. Das hat schon ein paar Jahre gedauert. (Nicola, 21-26)

It took Anika some time to find her own way of dealing with her infection as opposed to worrying about what others might think of or expect from her: “Erst ein halbes Jahr später habe ich gemerkt, dass ich mich so anpasse wie man sein sollte, wie die Gesellschaft das vielleicht sieht” (Anika, 157-158). She continous: “Ich nähere mich mir selber an. Ich habe mich lange mehr darum gekümmert, wie es den anderen damit geht, wenn ich es denen sage, weil ich vom Typ so bin. Jetzt frage ich mich so langsam, was hat das eigentlich mit dir gemacht? Warum tut das immer noch so weh?" (Anika, 183-187). She concludes: "Es gibt so Sachen, die passieren dir einmal und dann kommst du damit klar und dann hört das auf. Aber HIV ist so eine Sache, die hört in dem Sinne nie auf. Es ist die Wiederholung, die weh tut" (Anika, 192-194). Being able to maintain rational arguments, Ansgar could convincingly discuss the issue of living with HIV today with others, without completely embracing the situation himself: "Das war auch komisch, denen konnte ich ganz klar sagen, ich kann damit alt werden, das ist kein Ding, mach dir keine Sorgen. Aber ich selbst konnte es zu dem Zeitpunkt noch nicht leben. Das kam erst später" (Ansgar, 273-275). Ingrid had similar experiences considering her desire to have children. She explained the disconnect between her rational arguments and her emotional acceptance as follows:

> Also ich habe viele Jahre Dinge gefordert, die ich mir selbst nicht erlaubt habe. Ich bin aufgestanden und habe gesagt, jede Frau hat das Recht ein Kind zu bekommen. Da hat niemand etwas zu sagen. Ich hätte es mir selbst aber nie erlaubt. Es gab diese Kluft zwischen dem politischen Engagement und der Forderungen und dem was ich für mich selbst in Anspruch genommen habe oder mir überhaupt vorstellen konnte, in Anspruch zu nehmen. (Ingrid, 44-49)

For Ingrid the turning point came slowly. Only when her gynecologist told her that she could have a natural childbirth without having a cesarian did she finally grasp that she is non-infectious:

> Das verrückte ist, im sechsten Monat hatte die Gynäkologin mir gesagt, wenn ich möchte, dann könnte ich spontan gebären. Das habe ich aus Sorge abgelehnt. Ich wäre die dritte Frau in dieser Stadt gewesen. Ich wollte dann doch ganz sicher gehen. Habe dann aber mit meinem Mann das Gespräch gesucht. Bei einer Geburt, da gibt es doch Flüssigkeiten, Druck, Reibung, all die Komponenten, die es braucht. Wenn ich das darf, dann stimmt das. Da ist der Groschen gefallen. Was ich vorher schon wusste und argumentieren konnte, aber Gefühlsmäßig kam es noch nicht an. Erst mit dieser Information, dass ich spontan gebären darf. Seither haben wir kondomlosen Sex, aber jetzt sind die Kinder schon da. Seitdem ich weiß, dass ich spontan gebären kann, ist mir klar, ich bin keine Virenschleuder. (Ingrid, 96-106)

She stated that until then, her doctor had to inform her several times: "Im Jahr 2000 habe ich das erste Mal davon gehört und ich brauchte drei Jahre und diese Information dazu um das empfinden zu können und nicht nur zu wissen." (Ingrid, 106-108). Some participants were diagnosed not even a year before the interview. Those participants considered themselves in the beginning stages of a progression with possible unexpected turns, realizations and experiences yet to come:

> Bei mir ist es so, dass ich jetzt in den zehn Monaten, in denen ich das mache, damit lebe und damit auch meine Erfahrungen sammle und sammeln werde. Ich stehe auch erst am Anfang, wenn man das so sagen kann. Immer noch, denn ich glaube zehn Monate sind jetzt auch nicht so lange. Das ist ja jetzt noch relativ frisch. Da werden sicherlich in Bezug darauf auch noch Situationen kommen, die ich nicht einschätzen kann, mir noch nicht vorstellen kann. (Till, 734-739)

For two years – even after he started ART and medication resulted in an undetectable viral load – Collin avoided accepting his HIV infection: “Es hat zwei Jahre gedauert, bis ich mich wirklich mit dem Thema beschäftigt habe. Es war eher wie etwas im Hintergrund, was da ist, aber man nicht wirklich akzeptiert. Nach dem Testergebnis, aber auch nachdem die Therapie angefangen hat und die Werte runtergegangen sind. Man wird halt jeden Tag daran erinnert” (Collin, 10-14). There are indications that participants struggled to fully accept the status of being non-infectious, as Anika pointed out: “Ich tue es mir schwer zu sagen, ich bin nicht infektiös. Das kommt aber vielleicht auch daher, dass ich aus einem medizinischen Bereich komme” (Anika, 221-223). Communication is a crucial factor in coping with non-infectiousness: “Offen sein ist eine Sache, aber wie fühle ich mich dabei? Ich weiß, dass in den paar Wochen, wo es jetzt losging mit diesem Mann, dass es für mich total schwierig war und dass ich mir auch gar nicht sicher war, wie viel ich darüber mit ihm reden will” (Nicola, 73-76). Refering to the public discussion about non-infectiousness Nicola said: “Ich verstehe, dass es schwierig sein kann in Bezug auf Präventionsarbeit, weil manche sich vielleicht denken, na gut, jetzt gibt es schon so gute Medikamente. Ich glaube aber trotzdem, dass es ganz wichtig ist, offen darüber zu reden” (Nicola, 164-167).

4.5 Lack of Information by Practitioners

Participants expected to be informed about everything that concerns their HIV infection. Dialog with practitioners is crucial, as medical professionals are a main source for medical information and responsible for keeping their patients up-to-date. Among the participants, there were some positive reports on an adequate dialog about non-infectiousness, mainly from participants with previous knowledge on this topic or female participants with the desire to have children. Others, however, made explicit remarks about not having received adequate information concerning non-infectiousness from their practitioners. The lack of information was sometimes reflected upon with surprise, sometimes with desinterest and sometimes with anger.

Example of a Theme Cluster with Associated Formulated Meanings	
Lack of Information by practitioners	Emphasis on risks
	Misleading information
	No information on non-infectiousness
	Information only in reply to a question
	Dialog in conjunction with recreational health
	Censored information
	Information without further explanation
	Information only in acute situations
	Alternative sources for information

Figure 4.5 Theme Cluster: Lack of Information by Practitioners

In some cases information was apparently only given in reply to a question. Ansgar does not remember his practitioner addressing the topic of non-infectiousness during his consultations. He assumed that it was up to him to ask the right questions:

> Wir haben da gar nicht drüber gesprochen. Sie hat immer gesagt, haben sie Fragen. Es hätte ja auch immer die Möglichkeit gegeben, eine Frage zur Nichtinfektiösität zu stellen. Sie hat mir das am Anfang gar nicht gesagt. Also nicht direkt. Was sie damals gemacht hat, sie hat mir die Prophylaxe mitgegeben, falls es dann doch einmal passieren sollte, dass man ohne Gummi miteinander schläft, aber mehr auch nicht. Sie hat mir nie erzählt, dass ich nicht infektiös bin. Aber wieso, weshalb, mit welchem Hintergrund, wir haben hauptsächlich über die Nebenwirkungen gesprochen und wie sich mein Blutbild dann mit der Zeit positiv verändert hat. Über solche Dinge. (Ansgar, 224-232)

However, in acute situations participants did become informed. It took a risky situation under the influence of alcohol in which Ansgar and his partner did not use a condom for his physician to finally inform him that he was already non-infectious:

> Zu dem Zeitpunkt war ich nicht infektiös, trotzdem war die Panik groß und wir haben da echt zwei Monate geschwitzt. Dadurch habe ich dann auch erst erfahren, dass man unter der Therapie nicht infektiös sein soll. Das war dann natürlich eine Situation in der mich das interessiert hat. Das hat uns beide in der Situation dann auch sehr beruhigt. Danach wurde mir das erst bewusst. Das sind jetzt zweieinhalb Jahre, wo mir das bewusst ist, dass man dann nicht infektiös ist. Aber ich handle trotzdem als wenn ich infektiös wäre. (Ansgar, 209-214)

Even at the time of the interview Ansgar was in doubt: “Nein, das hat sie mir nicht gesagt. Vor allem, ist das auch wirklich so, dass man im Sperma keine Virenlast hat? Gar nichts?” (Ansgar, 245-247). He stated that based on his experience he always acted as if he was infectious even if he knew that he was not: “Es hätte nichts an meiner Verhaltensweise geändert. Mir war von Anfang an klar, ich muss andere schützen und mir war klar, ich muss mich schützen, weil sie das von Anfang an kommuniziert hat” (Ansgar, 240-242). Collin reported a similar experience with his practitioner: “Der Arzt den ich da hatte war auch nicht wirklich gut. Der hat nur immer gefragt, ob ich Fragen habe. Ich war da recht schüchtern" (Collin, 9-10). He was informed about non-infectiousness sometime after beginning medical therapy: "Ich habe vor zwei Jahren das erste Mal von der Nichtinfektiösität erfahren. Da hatte ich schon mit der Therapie begonnen" (Collin, 25-27). He continues: "Das mit der Nichtinfektiösität hat mein Arzt gar nicht kommuniziert. Ich glaube, da wissen auch ganz viele Leute nicht Bescheid. Viele Leute haben immer noch das Klischee aus den Achtzigern im Kopf. Die, die jetzt nichts direkt damit zu tun haben oder keine Leute kennen" (Collin, 20-24). The issue of censored information becomes evident in Ingrid's statement:

> "Zensur kommt nicht in Frage. Ganz prinzipiell. Ich lebe nicht in einem Land, in dem Zensur etwas zu suchen hat. Information muss zugängig sein. Wenn ich heute erfahren kann, dass ich nicht infektiös bin, möchte ich morgen auch erfahren können, dass Küsse vielleicht doch gefährlich sind. Ich möchte alle Informationen haben. Nur so können wir adäquat einschätzen." (Ingrid, 155-159)

Considering the responsibility of patients, Ingrid continues: "Information ist für alle da. Es geht euch einen Dreck an, wer wie damit umgeht. Das steht auf einem anderen Papier. Ich will keine Ärzte haben, die sagen, das sind gute Patienten, denen sage ich das, das sind schlechte Patienten" (Ingrid, 161-164). She reasoned how this topic should be addressed: "Stelle alle Informationen zur Verfügung, aber die Entscheidung liegt beim Einzelnen. Und die Diskussion war ganz schwierig im Zusammenhang mit, wie kommuniziert man dann. Das ist ja noch heute das Thema" (Ingrid, 168-171). She added about her and her acquaintances' confidence in scientific proof: "Es ist lustig, dass in meinem Umfeld niemand an den Fakten gezweifelt hat. Ich will jetzt nicht sagen, dass meine Verwandtschaft medizinhörig ist, aber sicher mehr wissenschaftlich orientiert als gläubig. Die interessiert Fakten. Das ist keine Glaubensfrage, sondern da stehen Studien dahinter" (Ingrid, 121-125). However in some consultations, even when the main facts were given there was still an emphasis put on risk: "Aber sie hat auch klar und deutlich gesagt, dass das jetzt nicht heißt, nur weil man unter der Nachweisgrenze ist, dass man sinnfrei durch die Gegend huren kann. Sie hat mir gesagt, dass immer ein Restrisiko bleibt" (Till, 615-618). At the same time alarming information on multiple HIV infections was given in a moralizing manner:

> Sie hat auch gesagt, dass es wünschenswert wäre, den Sex mit Kondomen zu machen, weil man sich nicht noch einen anderen Virustypen einfangen will und die eigene Medikation damit in Gefahr bringt. Das ist dann das eine, was auch noch passieren kann. Dann stecke ich mich mit einem anderen Typ Virus an und der mutiert auch noch irgendwie und dann ist mein Medikament unwirksam. Wenn ich Glück habe, finde ich ein anderes Medikament, was anspringt, wenn ich aber Pech habe, eben nicht. Und dann bin ich natürlich gefuckt und darauf habe ich keine Lust. Das hat sie schon deutlich gemacht. Das sollte sie aber auch als Ärztin. Das erwarte ich auch von einer Ärztin, dass sie mir da ein bisschen ein schlechtes Gewissen macht. (Till, 618-627)

For most participants, sources for detailed information on the current scientific state on HIV/Aids were institutions like Deutsche AIDS-Hilfe e.V. Hagen said: “Von EKAF habe ich dann das erste Mal im Waldschlösschen erfahren. Zu dem Zeitpunkt habe ich mich im Privaten nicht so damit auseinandergesetzt. Die letzten zwei Jahre fange ich auch an mich privat mehr mit HIV und Aids auseinanderzusetzen, in die Thematik reinzukommen und mich mehr zu engagieren” (Hagen, 282-286). Olive stated after her doctor’s initial counseling for her and her partner: “Alles andere haben wir durch die Seminare der AIDS-Hilfe mitbekommen” (Olive, 35-36). PLHIV often rely on themselves when it comes to researching, as Alex states: “Von meinem Arzt? Nein, ich habe selber sehr viel recherchiert.” He continues: “Ich habe viel darüber gelesen und auch mit meinem Arzt darüber geredet. Er sagte, ja, es gibt diese EKAF Geschichte. Eine richtige Erklärung von ihm habe ich nicht bekommen” (Alex, 44-46). Alex listed his sources of information: “Ich habe sehr viel Kontakt zum Gesundheitsamt in [German city] und zur Aids-Hilfe und zu vielen Leuten außerhalb [German city]. Ich lese auch viel im Internet und nehme in verschiedenen Städten an Seminaren teil. Ich bin auch Mitglied einer afrikanischen Selbsthilfegruppe” (Alex, 40-44). Hagen stated that he had to change his practitioner due to professional and personal differences: “Nein, sowohl menschlich als auch von der Fachkompetenz her. Mein Arzt kam mir körperlich zu nahe und das ist nicht wirklich professionell” (Hagen, 300-301). Unfortunately, only afterwards did he come to realize what he was missing in his treatment: “Nach dem Wechsel wusste ich auf einmal, was eine Viruslast ist, auf welche Werte es wirklich ankommt, dass es eben auf die Helferzellen ankommt, auf die Prozentzahlen und wie, wo, was eigentlich wirklich wirkt. Das wurde in drei Monaten bei meinem vorherigen Arzt nicht einmal thematisiert” (Hagen, 304-307).

4.6 Limited Awareness in Society

In social interactions the participants were time and again confronted with the general lack of awareness of this subject in society. While accepting the necessity to talk about their status to raise awareness and sometimes enjoying it, many participants experienced difficulties bridging the gap between what they know and what the others know about HIV/Aids.

Example of a Theme Cluster with Associated Formulated Meanings	
Limited awareness in society	Ignorance or partial knowledge Only vulnerable groups are informed Justification or defense Raising awareness Stigma and discrimination Limited experience and knowledge for informative arguments Conflict of social roles

Figure 4.6 Theme Cluster: Limited Awareness in Society

By its very nature, the subject of non-infectiousness challenges social interaction on different levels. Besides sexual contacts, the participants are repeatedly confronted with other people's unawareness about the current state of scientific knowledge on HIV/Aids in everyday life situations. While feeling relatively comfortable sharing information with acquaintances, friends and families, the participants also found themselves in situations where they felt pressured to defend themselves, and were faced with stigma, fear or false preconceptions. Among vulnurable groups this is considered to be less of a problem. Nicola stated: "Das schwierige daran, finde ich, ist, dass wir unter uns über die Nichtinfektiösität Bescheid wissen, aber die Öffentlichkeit halt nicht. Es ist ein wichtiges Thema und immer wenn ich überlege, mit jemandem zusammen zu sein, muss ich das erklären" (Nicola, 26-29). She also gives an example of meeting a sexual partner, who reacted positively to this information:

> Als wir uns bei ihm getroffen haben und es klar war, dass ich über Nacht da bleibe und dass etwas passieren könnte, habe ich ihn gefragt: „Sag mal, weißt du eigentlich, dass ich aufgrund meiner Behandlung nicht ansteckend bin?" Er hat das verneint, sich aber darüber gefreut. Ich hatte das Gefühl, es macht ihm keine Angst. Also es waren meine Ängste und Gedanken. (Nicola, 41-45)

In intimate situations, non-infectiousness is a relief for HIV-positives and their partners. However, the obligation of informing other people can be quite challenging, as Nicola says:

> Ich wünsche mir, dass darüber mehr in der Öffentlichkeit geredet wird. Das Statement der DAH kam ja Ende Oktober heraus. Das war zehn Tage nachdem ich ihm erzählt habe, dass ich nicht ansteckend bin. Das hätte ich ihm am liebsten gleich geschickt, aber das habe ich nicht gemacht. Da hätte ich das Gefühl gehabt, dass ich mich rechtfertige. Ich habe das nicht gemacht. (Nicola, 139-144)

Even though Nicola is a political HIV activist she sometimes struggles with disclosing her serostatus as a private person. However, being politically active gave her the strength and rhetorical skills to discuss it with people who are uneasy with this topic: "Ich habe natürlich eine Privatsphäre und ich gehe jetzt rum und stelle mich vor und sage gleich, dass ich HIV-positiv bin, aber es spielt für mich schon so eine große Rolle, dass ich mich halt entschieden habe, diese Arbeit zu machen. Ich glaube, dass mir das sehr geholfen hat, mit Leuten zu argumentieren, die nicht damit umgehen können" (Nicola, 107-112). While having experience herself as a political activist, Nicola realized that persons less prepared might shoulder an extra burden shortly after their positive testing and might feel less confident in discussing this topic adequately. She shared an everyday life experience that revealed the lack of knowledge among medical staff two years after the Swiss statement was released:

> "Es gab einen Moment, da bin ich mit einer Verletzung zum Arzt. Ins Krankenhaus wollte ich nicht. Und die Schwester hat mich bei einer großen offenen Wunde ohne Handschuhe verbunden. Daraufhin habe ich ihr gesagt, dass ich HIV-positiv bin und dass es mir lieber wäre, sie würde Handschuhe anziehen und zwar weniger wegen ihr sondern wegen mir, weil ich in Therapie bin. Sie ist käsebleich geworden. Ich hab ihr nicht gesagt, dass ich auch Krankenschwester bin. Am nächsten Tag habe ich sie dann noch einmal darüber aufgeklärt, dass ich unter der Nachweisgrenze bin und ihr gesagt, dass ich sie nicht schocken wollte. Sie hat sich bedankt, aber es war völlig klar, dass sie keine Ahnung hatte, wovon ich rede. Und das war vor zweieinhalb Jahren in einer Arztpraxis. Ich habe mir durch meine politische Arbeit ein Selbstbewusstsein und ein Wissen angeeignet, mit dem ich sicher argumentieren kann, was andere vielleicht nicht können. Und wenn ich schon in so eine blöde Situation komme, wo ich denke, dass ich zurückgehen muss, um sie beruhigen muss, weil sie echt keine Ahnung hatte, dann ist das sehr bedenklich. Das ist nicht meine Verantwortung." (Nicola, 167-181)

In several interviews, presumptions based on the way HIV/Aids was perceived in the Eighties and Nineties were mentioned. From the participants' perpective public awareness is only shifting slowly towards a modern understanding of HIV/Aids; especially in rural areas and among less vulnarble parts of the population, as Collin states: "Aber wir sind ja auch in [German city]. Hier sind so viele Schwule und so viele Positive. Das ist noch einmal was anderes als wenn man jetzt vom Dorf kommt" (Collin, 109-111). When asked how he experienced public awareness of this topic, he elaborates: "In der Schwulenszene oder bei Leute, die Sex mit vielen verschiedenen Partnern haben, aber bei Heteros, die zu Hause mit ihren Kindern sitzen, ist das wahrscheinlich ein anderes Thema. Auch wenn sie in Berlin leben. Das hängt davon ab, inwiefern das Thema im Alltag präsent ist, ob man Leute kennt oder nicht, die einem das schildern" (Collin, 141-145). Collin admitted that he did not know the details about non-infectiousness either: "Ich wusste damals nicht wirklich Bescheid. Man wusste halt, was man in den Medien hört, aber nicht die Details oder wie das mit den Medikamenten ist" (Collin, 6-8). Most men Till had sex with knew about the protective effect of medical therapy. However, he counts himself among those people who were not aware of this phenomenon until they were affected themselves:

> Ich hatte nur ein- oder zweimal den Fall, wo denen das nicht bewusst war. Die wussten schon, dass man das mit Medikamenten behandeln kann, die wussten dann aber nicht, dass man unter der Nachweisgrenze sein kann. Da sind Worte gefallen, das haben die in ihrem Leben noch nie gehört. Nur muss ich zugeben, bevor ich in diese Situation geraten bin, habe ich auch nichts davon gehört. Also, ich wusste das auch nicht. Da bin ich auch ganz ehrlich. Ich habe das nie gehört, unter der Nachweisgrenze. Was meint ihr überhaupt damit? Für mich war eigentlich klar, du hast HIV, na das hast du dann. Das einzige, was das Medikament macht, das hält es in Schach. Also es erhöht die Virenanzahl nicht. Ich wusste aber nicht, dass es die Virenlast senkt. Das war mir nicht bekannt. Und dass es dann auch so weit geht, dass es unter die Nachweisgrenze geht, dass es praktisch mit einem Schnelltest überhaupt nicht nachweisbar ist. Das war mir alles nicht bewusst. Bei den meisten, ich sage mal bei 80 Prozent, die wussten das. (Till, 359-371)

Damon described the atmosphere at work and why he would not want to disclose his HIV status there: “Das ist auch ein relativ heterosexuelles Umfeld. Ich glaube nicht, dass ich ein großes Problem mit Diskriminierung hätte, aber ich sehe auch keine große Notwendigkeit. Also ich erkläre ja gerne, aber am Arbeitsplatz muss das nicht sein und es reicht, wenn ich das den Leuten erkläre, die mir etwas bedeuten” (Damon, 219-224). Related to this, Hagen described his workplace situation, stating that he revealed the information about ART-related non-infectiousness during his job interview to prevent fear and misunderstandings:

> “Die Geschäftsführung wusste Bescheid, der Vorstand wusste Bescheid und meine direkte Vorgesetzte wusste Bescheid, sonst niemand. Aber die sind ganz normal mit mir umgegangen. Die haben am Anfang viele Fragen gestellt nachdem ich mich geoutet habe. Einfach nur, um bestimmte Dinge zu wissen. Immer so kleine Fragen in der Anfangszeit und irgendwann war das kein Thema mehr. Da wurde nicht nachgefragt. In dem ersten Gespräch habe ich auch gesagt, dass ich unter der Nachweisgrenze und nicht infektiös bin. Ich habe das gesagt, weil es mir auch wichtig war, um Angst zu nehmen, mögliche Panik vorzubeugen, aber thematisiert wurde das danach nie wieder.” (Hagen, 374-383)

About his acquaintances, Alex stated: “Viele sind auch nicht gut informiert. Jedes Mal wenn wir uns treffen, sind sie ein bisschen neugierig und jedes Mal, wenn wir uns treffen, muss ich die neuste Entwicklung, die Forschung, den heutigen Stand berichten und Erklärungsarbeit für diese Leute machen” (Alex, 103-106). Especially if one is not versed in scientific or medical knowledge about HIV, it is difficult to give details or explain likelihoods of non-infectiousness. Anika described a situation with her brothers: “Meine Brüder habe ich so aufgeklärt. Das ist vergleichbar mit einer chronischen Erkrankung. Ich nehme meine Tablette jeden Tag, ich habe eine normale Lebenserwartung und gelte als nicht infektiös” (Anika, 213-215). As a doctor she experienced the quandary of being seen as a knowledgable and trust-worthy medical professional while living with personal insecurities: “Meinem letzten Freund habe ich erzählt er könne mich fragen, das recherchieren oder auch mit meiner Ärztin reden. Das hätte ich gut gefunden, wollte er aber nicht. Er vertraue mir. Ich sei ja auch Ärztin. Da komme ich dann in eine blöde

Doppelrolle und das möchte ich eher nicht" (Anika, 242-245). Anika stated that she used likelihoods and probability to explain the risk of infectiousness:

> Dann argumentiere ich mit Wahrscheinlichkeiten. Man sagt unter eins zu hunderttausend ist die Wahrscheinlichkeit. Es ist wahrscheinlicher, dass du bei einem Autofahren einen Unfall hast, als dass du dich bei mir ansteckst. Ich glaube Flugzeugabstürze sind noch ein bisschen seltener. Die sollen sich dann selber aussuchen, wie kritisch sie das sehen wollen. Es gibt Leute, die spielen Lotto und glauben daran. (Anika, 216-221)

However, Anika stated that for her not every risk could be excluded: "Dann hätte ich schon irgendwie das Gefühl, dass ich jemanden belügen würde, wenn ich das komplett ausschließe" (Anika, 224-226)

4.7 Adjusted Protective Behavior

HIV infection and ART-related non-infectiousness have an impact on protective behavior, which can be devided into three subcategories. First, there are various situations, in which participants rely on therapy as a protection method. Second, mainly MSM practice serosorting as a method of protection, especially after a positive HIV testing. This is also the case among the participants in this study as the medical therapy made the participants more confident in doing so. Third, the risk of STI transmission became more relevant for the participants; for example, the avoidance of viral load blips or multiple HIV infections. It is of interest here as to what extent an undetectable viral load influences individual protective behavior. Some participants stated that they generally were less afraid of transmitting the virus during sex without condoms and subsequently did not use condoms. However, it is difficult to say if those participants who tended to neglect condoms after the HIV diagnosis did not already neglected them before. Doubts and difficulties in serodiscordant relationships were also expressed. The participants who tended to serosort, emphasized the importance of sexual education, sexual communication and reliablity. Behavior in cruising locations tended to be more risky. Additionally, a few participants only vaguely mentioned legal considerations in regard to the criminalization around HIV transmission. In most interviews, the relevance of STI and multiple infections varied. While multiple HIV infections were mentioned as a concern, the bigger concern for participants was the risk of STI transmission, specifically Hepatitis C.

Selected Examples of Significant Statements and Related Formulated Meanings	
Also so war das jedenfalls bei mir, dass sich mein Spaß am Sex wieder erhöht hat, so dass ich mich auch irgendwann darauf gefreut habe, unterhalb der Nachweisgrenze zu sein. Das geht ja heutzutage ganz schnell. Für den einen nach einem viertel für den anderen nach einem halben Jahr. Und dann natürlich auch, wie eine riesige, verlockende Leberwurst vor meinem Maul, wieder ohne Kondom vögeln zu können. Natürlich vernünftigerweise nur in Ausnahmefällen und mit Leuten die man kennt und nicht in Situationen, wo man sich unsägliche Schmierinfektionen einfangen kann. Dafür sind Kondome nach wie vor gut. (Elmar, 70-78)	Sexual desire increases as the body recovers in the beginning of ART. The option of having sex without condoms under certain circumstances is considered.
I slept with seven or eight people that were on medication. I didn't want to go too far into it because I didn't want to pry into the whole personal aspect of living with a virus you can't get rid of. Now that I'm there I tend to serosort, so it's not a problem for me to talk about viral loads and detectable levels and what medicines you're taking. (Andrew, 89-93)	Communication barriers are broken down and protective behavior consists of informative discussion and serosorting.

Figure 4.7 Related Formulated Meanings: Adjusted Protective Behavior

4.7.1 Therapy as a Protection Method

The possibility of having sex without condoms appealed to most participants. Consequently, condoms were omitted in various situations, while the method of protection through therapy was used in accordance to safer sex rules. The notion of finding pleasure in an otherwise devasting experience was mentioned repeatedly, and in this context ART and its effects come with a sense of relief. Those participants, who made use of this method, did this based on a less worrisome attitude and increased self-esteem. Some found an arrangement within a monogamous relationship; others found arrangements with exclusive partners, while having sex with others. In some cases, no agreement could be found within a relationship, resulting in an ongoing use of condoms in respect to the HIV-negative partner's doubts and fears. Some participants reported on not communicating their HIV status in certain settings, such as darkrooms and other cruising situations, nonetheless refering to their undetectable viral load, but also to the assumption that in this setting MSM are either HIV-positive themselves or at least know about the risks.

The option of protected HIV-serodiscordant sex based on medical therapy entails the question of further condom use. Participants who neglected using condoms also expressed an increase in self-esteem. For example, Damon challenged his sexual partners to not use condoms: “Ich fühle mich deutlich selbstsicherer, gerade in Gesprächen. Insbesondere mit potentiellen HIV-negativen Sexualpartnern. Es hat den Makel für mich emotional reduziert” (Damon, 108-110). He continued to communicate condomless sex on online-dating pages more aggressively. Other participants expressed their relief, too. Till admitted that he was surprised, as he did not know about the possibility of protection based on medical therapy. The option of condomless sex appealed to him: “Teilweise war es auch positiv das zu hören. Na klar, weil man auch die Denkweise hat, na gut, man kann ja ungeschützten Sex haben” (Till, 591-593). Hannes admitted that even though he had doubts, the “studies on this subject brought forth remarkable relief (cf. Hannes, 96-99). Andrew reflected on the emotional conflict in using condoms: “As much as people like to shy away from it, nobody wants to wear a condom. It’s not that they are not sexy. It just adds an extra level of something. You have this mentality of: I’m putting a barrier between two people and that’s supposed to be the one thing that protects me. I don’t know. I feel like it’s too simple” (Andrew, 174-178). Mostly in seroconcordant relationships or with seroconcordant sexual partners, the participants reported having sex without condoms (cf. Enzo, 12-13; Hagen, 387-388; Alex, 71-72). Enzo reflected on his considerations:

> Oder ob man dann nicht gleich sagt, jetzt bin ich eh schon positiv und muss jeden Tag die Pille schlucken, dann kann ich wenigstens die Kondome sparen. Das ist schon so ein Gedanke, der da ist. Da will ich sozusagen schon einen Gegenwert haben. Also zu sagen, scheiß auf den anderen Rest. Auf der anderen Seite gibt es Momente, wo ich sage, jetzt zu all den Pillen auch noch Antibiotikum zu nehmen, das muss auch nicht sein. Also das schwank immer so ein bisschen zwischen jetzt will ich auch drauflosvögeln wollen, auch als Kompensation, und eben zu sagen, jetzt musst du noch ein bisschen mehr auf dich Acht geben, weil die Leber muss man nicht noch mehr belasten. Man schwankt zwischen diesen beiden Polen. (Enzo, 283-292)

For some participants the displeasure with condoms was also present before the HIV positive test result (cf. Till, 586-589; Hagen, 26-33). For Damon, the HIV infection and medical therapy resulted in the desire to only have sex without condoms: “Ich habe einfach den Spieß umgedreht. Anstatt dass ich mir von einem HIV-Negativen sagen lassen muss, nein, ich habe Angst mich anzustecken, deswegen will ich nicht mit dir schlafen, habe ich mich eher in die Position gebracht sagen zu können, nein, ich habe keinen Bock Gummis zu nehmen, du schon, deswegen will ich nicht mit dir schlafen” (Damon, 138-142). He elaborated: “Ich mache keinen großen Hehl daraus, nicht auf Gummis zu stehen. Wenn jemand darauf besteht, dann sage ich, gut für dich, mach das ruhig weiter so, aber wir zwei werden vermutlich keinen Spaß miteinander haben. Wenn ich Spaß an Gummis gehabt hätte, dann wäre ich wahrscheinlich nicht HIV-positiv geworden” (Damon, 132-136). Damon also expected his new HIV-serodiscordant partner, who also happened to be his long-term friend, to agree with him on this topic: “Er verlässt sich auf den Stand der Wissenschaft, der sagt, wenn gewisse Bedingungen eingehalten werden, kann er sich nicht anstecken. Das ist alles noch sehr frisch. Wir hatten tatsächlich erst einmal ungeschützten Sex, aber das war dann selbstverständlich” (Damon, 260-263). He elaborated on his motives, which shows that his behavior is not a result of his undetectable viral load, but rather an intrinsic desire:

> Ich muss ganz ehrlich sagen, ich glaube nicht, dass ich das so entwickelt hätte, wenn er eine andere Haltung dazu hätte. Da schäme ich mich ein bisschen für mich selbst. Wenn er gesagt hätte, wir nehmen Gummis, weil ich Angst habe, dann hätte ich mich nicht auf das Zusammensein eingelassen. Wenn ich ganz ehrlich bin, ich könnte es mir nicht vorstellen, den Rest meines Lebens mit ihm zusammen zu sein und mit Gummi zu vögeln. Ich hätte keinen Bock drauf. Ich hätte es nicht gemacht. (Damon, 263-269)

He reported on the personal history and arrangements with his partner:

> Wir haben schon jahrelang immer ohne Gummi miteinander geschlafen, auch als wir noch beide negativ waren. Ich habe mir schon vor Jahren überlegt, wie ich mich dazu verhalten würde, wenn er positiv wär. Ich habe damals eigentlich schon gesagt, dann würde ich mich lieber dem Risiko aussetzen, mich anzustecken als gemeinsam mit ihm einen Gummi zu nehmen. Mir war das klar. Heute sagt er das gleiche: „Ich weiß, eigentlich kann nichts passieren. Ich weiß, es besteht ein theoretisches Restrisiko. Aber wenn ich es bekomme, dann lieber von dir als von irgendeinem anderen.“ (Damon, 292-299)

Several participants reported on condomless sex with HIV-negative partners. Till was meeting an HIV-negative friend regularly and they had sex without condoms. In this case Till accepted the method of protection through therapy: “Also mittlerweile ist das, kann man so sagen, so fuckbuddy-mäßig. Der Sex ist echt gut und der wäre nicht so, wenn es mit Kondom wäre. Das sage ich ganz offen und ganz ehrlich” (Till, 436-439). Conversations about residual risk were important to Till. Still, he struggled with the idea of practicing sex without a condom on a regular basis: “Aber ich hätte ein schlechtes Gewissen, wenn ich permanent ohne Kondom und ohne etwas zu sagen Sex hätte. Vielleicht nicht bei den ersten drei-, viermal, aber wenn da eine bestimmte Regelmäßigkeit zu erkennen ist” (Till, 638-640). When a potential partner approached Till to have sex without a condom for the first time, he felt the need to repeatedly inform him about the situation and possible consequences: “Der wollte unbedingt immungeschützten Sex haben und ich habe ihn mehrfach drauf hingewiesen, habe ihm gesagt, ich bin positiv, ich bin zwar unter der Nachweisgrenze, das heißt jetzt aber nicht, dass das jetzt easy going ist und nichts passiert” (Till, 411-415). Only when he was convinced his friend understood the situation fully, did Till agree to have sex without condoms:

> Aber er weiß halt auch klar und deutlich, was es bedeutet und dass noch ein Risiko da ist. Wenn ihm jetzt was passiert, wenn er es jetzt wider Erwarten kriegen sollte, würde ich mich sicherlich nicht so wohl fühlen. Aber ich muss dazu sagen, in dem speziellen Fall würde ich mir nicht diese Schuldgefühle machen. Einfach aus dem Grund heraus, weil ich ihm mehrfach gesagt habe, was ich zu sagen habe und dass er glaube ich erwachsen genug ist. (Till, 425-430)

In relationships most participants stated that they found a mutual agreement with their partner on whether to use condoms or not. Unna's husband apparently did not want to accept restrictions within their sex life. Accordingly, they decided to have sex without condoms. However, she also stated: "In der Partnerschaft ist es [HIV infection] immer ein Thema – unbewusst oder bewusst." (Unna, 68-69). She revealed her tendency to brood over issues and stated about her partner: "Er hat am Anfang den Wunsch geäußert, lieber auch positiv zu sein, da dann alles leichter wäre, weil ich so ein Kopfmensch bin und mir so viele Gedanken mache" (Unna, 116-118). Other participants reported more difficulties with HIV-serodiscordant partners, as the HIV-negative partner did not always give his consent. Alex had unprotected sex with his wife before he was diagnosed HIV-positive and started using condoms afterwards when she was diagnosed HIV-negative: "Ich bin es nicht gewöhnt mit Kondom und jetzt bin ich dazu verurteilt" (Alex, 57-58). After they became aware of the Swiss statement, Alex did not want to continue using condoms: "Mit Kondom gibt es keine gute Qualität" (Alex, 69). But his wife reportedly wanted to continue: "Ich fühle mich nicht ganz wohl dabei, aber wenn ich muss dann muss ich das halt. Für meine Frau ist das eine ernste Sache. Als mir nach dem EKAF Statement gesagt wurde, das müsse nicht mehr sein, dachte ich, dass auch meine Frau damit einverstanden wäre. Aber meine Frau wollte nur mit Kondom Sex haben" (Alex, 61-64). Olive's partner was, according to her, also reluctant to take that step and thus they decided to keep on using condoms: "Er ist derjenige der noch Angst hat. Und es müssen ja beide einverstanden sein" (Olive, 74-75). However, she did talk about her desire to have sex without condoms: "Ich glaube, dass das EKAF-Papier stimmt, weil ich ungefähr sechs Monate ohne Kondom Geschlechtsverkehr mit meinem Mann gehabt habe und er nicht infiziert wurde. Ich glaube wirklich dran. Obwohl meine Viruslast sehr hoch ist und jetzt da sie fast Null ist, glaube ich, ich kann ihn nicht infizieren" (Olive, 70-74). She elaborated on the impact of HIV and the use of condoms on her sex life and her emotional state: „Aber diese Kondomnutzung beeinflusst einfach auch meine Lust. Das hat schon einen Einfluss auf unser Sexleben. Zum einen die Infektion für meinen Mann und zum anderen die Kondome für mich. Die Kondome reduzieren meine Lust. Ich fühle mich dann als gefährlich und sage dann, lieber nicht“ (Olive, 75-78). Nicola stated that she stayed in a relationship with the man who infected her, because she wanted to avoid dealing with the situation on her own. When they broke up after years, she found herself for the first time with an HIV-negative partner: “Erst jetzt kam ich selbst in die Situation und fand das sehr schwierig” (Nicola, 36-37). Enzo said about his situation with his partner after both were diagnosed with HIV at the same time: “Ich war auch ein bisschen froh, dass es uns beide gleichzeitig erwischt hat. Ich hätte es schwierig gefunden, wenn es nur einer von uns gewesen wäre. […] Wir hatten dann zumindest keine Sorge, dass man sich noch anstecken könnte. Wie geht man damit um?” (Enzo, 198-203).

Several participants mentioned legal considerations, which might interfere with individual sexual behavior (cf. Hannes, 98-99; Ingrid, 62-65). Andrew described his experience in the United States and the according legal framework: “If you have sex with someone and you lie about your sero-status that’s endangering that person’s life and you could be put in jail. It became something that I would always ask. Because if they lie to me…nice try, sweetheart” (Andrew, 100-102). He compared this with the situation in Germany and concluded that here “people don’t actually ask. They are just going at it. Maybe it’s because there is not so much legal requirement” (Andrew, 147-148). He elaborated:

> I’m always very upfront. It’s easier that way. Whenever I have a profile on anything it’s clearly stated in every single online profile that I have, positive, pos for positive or pos for positive friendly. No bullshit, I get it out of the way immediately. Not a lot of guys that I met here that are German and are born here really handle that. And I have met a lot of positive people. They don’t have that need. They don’t feel that need. (Andrew, 150-155)

In regard to HIV transmission, many participants still used condoms during serodiscordant sex or when the serostatus of the partner was unknown (cf. Hannes, 110-111; Ansgar, 280-283). However, there were also contradictions in regard to the consistency of condom use. For example, Till insisted on the importance of condom use: “Da gibt’s aber auch keine Diskussion. Auch wenn ich unter der Nachweisgrenze bin, bleibt immer ein gewisses Restrisiko, auch wenn das sicherlich prozentual so gering ist und es auch noch mal darauf ankommt, wer ist jetzt aktiv und wer ist passiv” (Till, 403-406). Only in another context he talked about a serodiscordant regular sex partner, with whom he did not use condoms (cf. Till, 434-438). Altogether, he expressed doubts considering the impact of non-infectiousness: “Ich weiß nicht, ob es für mich irgendeine Auswirkung hat. Ich glaube jetzt so gar nicht, dass es eine Auswirkung hat. Ist meine Meinung. Ich sehe jetzt nichts, nicht so bewusst. Sie erlaubt mir ja nun auch nicht mehr. Eigentlich, wenn man es genau betrachtet. Wir denken teilweise, sie erlaubt uns mehr, aber das ist ja ein riesiger Trugschluss” (Till, 602-607).

4.7.2 Serosorting

Serosorting is a method based on the idea of reducing the risk of HIV transmission by chosing seroconcordant partners. Generally, there is a tendency among participants to choose sexual partners according to their HIV serostatus. Participants repeatedly mentioned either consciously looking for a seroconcordant partner or feeling relieved when their partner happened to be HIV-positive too and thus no cause for fear of HIV transmission. Enzo and his partner, who both tested HIV-positive at the same time, were figuring out and discussing a consistent agreement on their protective behavior with sex partners outside of their open relationship: “Auf der einen Seite unterscheiden wir viel mehr, ob wir Sex mit Positiven oder mit potentiell nicht HIV-Positiven haben. Also mit bewusst wissend HIV-Positiven oder mit nicht wissend HIV-Positiven, muss man ja sagen. […] Also das unterscheidet sich dann schon” (Enzo, 245-248). Before his HIV diagnosis Enzo protected himself by consistently using condoms and therefore did not have much interest in the serostatus of his sexual partners. Subsequently he kept the option open to have sex without condoms when serosorting: “Also das hat sich geändert. Der Status des Sexpartners hat Konsequenzen. Ich hatte auch noch keinen Fall, wo jemand positiv war und nicht in Therapie war. Ich weiß nicht, ob das nochmal einen Unterschied machen würde” (Enzo, 266-269). Alex decided to serosort after his marriage broke down and he experienced a few dysfunctional HIV-serodiscordant relationships. He wanted to avoid the problems that arose in these relationships: “Heute treffe ich nur positive Frauen, einige ab und zu. Wenn wir Sex haben, versuche ich in Erfahrung zu bringen, ob sie auch medikamenten- und therapietreu ist. Alle die ich kenne haben eine Viruslast unter der Nachweisgrenze. Und wir haben jetzt ohne Kondome Sex” (Alex, 88-91). He expressed difficulties in finding a serodiscordant partner: “Es ist schwer. Ich habe ein paar negative Frauen gefunden und getroffen. Einer habe ich gesagt, ich bin positiv. Sie ließ sofort die Finger weg und hat sich gleich von mir distanziert. Einer anderen habe ich das auch gesagt und für sie hieß das, Sex nur mit Kondom. Irgendwann klappte unsere Beziehung auch nicht mehr und wir haben aufgehört” (Alex, 82-86). Calculated risk is an essential aspect of serosorting. Andrew stated that his decision on whether or not he would use condoms is based on information about medication, recent lab tests, the number of sexual contacts and the risk of transmitting STIs:

> I feel what truly protects you is having an open dialogue with this other person. Having that connection where it's like, here is all the stuff that I come with, I want to see your cards too and then we go from there. We have an honest open conversation and say, I've been on medication for this long, the last time that I've had my labs done, this is what my levels were. I have slept with x number of people in the last time, so my chance of having Gonorrhea or Chlamydia or whatever else is very slim or maybe we should wear a condom. Or let's wait until after I get tested again and I'm sure that everything's ok. In this information age that we live in, I don't know, in a way it's more intelligent for me to have a conversation with people and have unprotected sex with someone that I trust and I know than having protected sex with a complete stranger. (Andrew, 178-188)

In this context, reliable intimate contacts are essential to maintain security. Outside of a relationship many participants favored to maintain networks where they could practice condomless sex with people they know. Clear advantages would be easy communication and quick feedback concerning STIs if necessary: "I prefer to have lovers that I sleep with exclusively. And they can clearly have other lovers too. It's like, I trust them because I communicate with them, I hang out with them, I'm friends with them, I know them. And they know me. Sure, random sex is random sex" (Andrew, 188-191). He described his idea of a sexual network as follows:

> It depends on the person and it depends on the situation. There were guys that I had long-term sexual relationships with, who are either also positive or are very well aware of my health status. They understand the risks and what it means to be undetectable. I tend to think less about wearing a condom, more "they know who I am, I know who they are". I have been with them for six months, a year, two years. Some of my longest standing lovers I never wear condoms with. (Andrew, 163-168)

Further aspects of importance are sexual education and sexual communication. Andrew criticizes a lack of conversation on sexual and protective issues: "But at the same time there are certain things people just don't do. They don't go to a bar and just ask. What's your status? When is the last time you got tested? Do you have condoms? I never hear these things asked. Ever. And I overheard some really interesting conversations in bars, especially with the sexual tourism in this city" (Andrew, 192-196). Elmar emphasized the aspect of personal contacts, addressing an emotional dimension: "Das ist ja dieses System, dass man sich kennen sollte. Ich finde, Sex ist etwas Persönliches. Was ich einfach unsympathisch finde, wenn man als Sexualpartner nur eine Art Leinwand ist, auf die der andere dann Vorstellungen projiziert, die nichts mit einem zu tun haben, sondern ausschließlich aus seinem Kopf und Gefühl heraus kommen" (Elmar, 369-374). Most participants generally saw it as their responsibility to communicate their HIV serostatus as early as possible, as Till stated:

> Klar, du hast dann auch weiterhin noch dein Sexleben. Das willst du ja auch haben. Wie das dann so abgeht, wie unvorsichtig manche sind und wie egal manchen das auch ist, fällt einem dann extrem auf. […] Ich werde und will kein Geheimnis draus machen. Also ich gehe relativ früh und offen damit um. Es ist jetzt nicht so, dass ich mit einem Zettel auf der Stirn rumrenne und damit hausieren gehe. Huhu, ich bin HIV-positiv. Das mache ich natürlich nicht. Aber ich versuche schon so früh wie möglich mit offenen Karten zu spielen. Ich möchte einfach die Gewissheit haben, dass ich nichts Falsches mache. Und ich mag niemanden anlügen. (Till, 166-175)

Among participants who frequent cruising locations, such as darkroom bars or public parks, the awareness of high-risk behavior in these locations was very present: "I definitely started barebacking more and not really caring about it as a top. But only in situations like in a dark room, where I feel like everybody who puts himself in this situation knows about HIV and either has it or doesn't care" (Robert, 157-159). Robert said he usually met his sexual needs in cruising situations: "I was never dating guys on Gayromeo [social network for MSM], meeting guys and fucking them without telling; as a kind of social dating, I would never do that. If I was dating someone, maybe it was at a dinner that it came up and I would always be honest about my status" (Robert, 159-162). About darkrooms Robert said, "But when you're in a darkroom or you're cruising somewhere it's not exactly like, 'by the way, I'm positive.' In a darkroom it's kind of like a buzz kill. Most of the time they are probably positive, too. That's just what I assume" (Robert, 162-165). Robert reflected on his risk behavior:

> And the people I have sex with are generally thirty to fifty years old, so I kind of assume that they know the risks involved in whether or not you're having protected or unprotected sex. I have people that I know that have unprotected sex with young guys in their early twenties. I would never. First of all, I'm not into guys like that. It's interesting. I remember when I was that age there were so many guys that I could tell were into me but didn't want to have sex with me and now I know why. They were trying to protect me or something. They were probably positive. I had this conversation with a friend. There were so many guys who would not even get near us because they were trying to protect us. (Robert, 107-115)

He implied the lack of change after his diagnosis:

> Honestly, I don't even think my behavior changed. My sexual behavior didn't change. First of all, I was more of a bottom anyways and I was never into younger guys. I didn't want to have sex with some twenty something guy who doesn't know any better and pass it on to him. As if it was ok to do that with somebody who is older. It's not! But that was my mentality at the time. But I wasn't really putting anyone at risk, so there's no need to talk about it or tell anyone. I did it for a long time. (Robert, 50-57)

After his positive test result, Damon too was more deliberately looking for bareback sex:

> Bei Barebackcity [social network for MSM who neglect condoms] gibt es einen sehr offenen Umgang mit der Thematik. Die Leute schreiben ihren HIV-Status zum Teil sogar mit Viruslast in ihr Profil. […] Ansonsten versuche ich Leute zu finden, die ungefähr so ticken wie ich, also halbwegsauf sich achten und auf was sie mit wem tun und die da einen normalen Ansatz dazu haben. (Damon, 148-158)

He already practiced high-risk sexual behavior before and visited bareback sex websites, however, he did not use these sites exclusively. Hagen justified his high-risk behavior by stating that he always communicated his HIV status: "Ich selbst habe mich nicht als Gefahr für andere werden lassen. So habe ich das damals gesehen. Wenn Leute sich von mir bare [without condom] ficken lassen wollten oder schlucken wollten habe ich gesagt, dass ich positiv bin." (Hagen, 104-108). He elaborated on his behavior in porn cinemas or darkroom bars: "Da bin ich von mir ausgegangen, ich wusste ja um das Risiko. Der wird hoffentlich genau so weit sein. Aber auch, weil ich wusste, ich bin unter der Nachweisgrenze" (Hagen, 343-345).

4.7.3 Relevance of STI and Multiple HIV Infections

One aspect that gains relevance in the discourse of protective behavior is the significance of STIs or multiple HIV infections. Based on information from his physician Ansgar mentioned that he worries about being infected with another genotype, while expecting to start a more promiscuous life as a single after his long-term relationship ended (cf. Ansgar, 215-217). While Hagen experienced various sexually transmitted infections, including contracting a Hepatitis C infection three times, he counted out the risk of multiple infections of HIV: "Ich habe keine Angst, dass ich mir irgendwelche Multiresistenzen zuziehe oder Sonstiges. Das wird schon so lange diskutiert, aber solange das eine Theorie ist, macht mir das keine Angst" (Hagen, 272-274). Several participants stated the necessity to use condoms in seroconcordant sex to protect themselves from further STI transmission. Urs said: "Wir benutzen trotzdem Kondome, weil es ja so viele andere Sachen noch gibt. Ich bin immer mal wieder in der AIDS-Hilfe und besuche auch Vorträge zu diesem Thema. […] Da ist doch neben HIV noch einiges was passieren kann" (Urs, 178-183). Whether or not different STIs were distinguished, a Hepatitis C viral infection was generally the main concern (cf. Till, 391-402; Ansgar, 282-283). Till stated that he still felt vulnerable to STI: "Nur weil man unter der Nachweisgrenze ist, ist man jetzt nicht unter einem unsichtbaren Schutzschild. Ich weiß nicht, ob die Therapie so viel geändert hat in Bezug auf mein Sexleben oder ungeschütztem Sexleben" (Till, 596-598). Andrew outlined his attitude: "I'm clearly very open about what it is that I have. I can get a print out of my last STD screening if you like. It's not really that big of a deal" (Andrew, 172-174). He mentioned his considerations living in a major city with a lot of sex tourism: "But I'm a picky bastard. I don't want Hep C. I don't want Chlamydia. I definitely don't want Gonorrhea, considering it's very close to being untreatable. And you can get that from a blow job" (Andrew, 197-199). Enzo poignantly resumes:

> Das Risiko an Mehrfachinfektion ist nicht so das Thema. Auch nach ärztlicher Beratung gilt das als sehr unwahrscheinlich und zu vernachlässigendes Risiko. Dahingehend haben wir keine Angst. Die Frage ist halt immer, von wegen STI oder nicht. Das ist halt so eine Sache, wo wir immer ein bisschen hin und herschwanken. Soll man doch zumindest Kondome benutzen? Andererseits hatten wir vorher auch trotz Kondom Tripper. Natürlich verringert es das Risiko, aber auch nicht so signifikant. Also dann ist eher Hepatitis C der problematischere Punkt. Bei Tripper oder Syphilis ist das Kondom eher begrenzter Schutz. Dann neige ich eher zu „muss man nicht unbedingt“. (Enzo, 249-258)

He elaborated on the discussion of wether or not it is necessary to use condoms:

> Weil man ohnehin schon immer aufgepasst hat, denkt man über STI nach. Aber auch da merke ich, dass ich auch da weniger drüber nachdenke. Also das mit dem Safer Sex hat ja bei HIV auch schon nicht so hundertprozentig funktioniert. Wie viel Sinn macht es, wenn man eh schon HIV-positiv ist, sich dann noch eventuell zu schützen oder das Risiko zu senken? Wobei man sich ja vor Syphilis und Tripper nicht wirklich schützen kann. Von wegen, das Risiko ist ein bisschen geringer. (Enzo, 277-283)

Some participants pointed out that due to regular and continuous check-ups there is less risk of STI transmission having sex with HIV-positive men under ART than with HIV-negative men: “Kondome benutze ich lediglich zum Selbstschutz. Um andere zu schützen, muss ich kein Kondom benutzen. Ich weiß, dass ich keine Syphilis habe, ich gehe ja auch alle Vierteljahre zur Blutuntersuchung. Das wird ja im Blick gehalten“ (Elmar, 366-368). Collin stated about a serodiscordant partner: “Der fühlte sich da schon fast sicherer als mit Leuten, die ihren Status halt nicht wissen. Wir gehen halt alle drei Monate zum Arzt. Und es ist ja nicht nur das, was untersucht wird. Es wird ja alles andere mituntersucht. Und eigentlich ist man da schon fast sicherer als bei Leuten, die nur einmal im Jahr zum Arzt gehen“ (Collin, 80-83).

4.8 Desire to Have Children

The desire to have children was a strong motivation for most women among the participants to rely on therapy as a method of protection. The participants had mixed feelings about this, e.g. fear of HIV transmission, healing, relief or joy. Several participants, singles as well as women in relationships, had sex without condoms based on their undetectable viral load. In the context of reproductive health, practitioners openly communicated non-infectiousness. In 2000, one year after the beginning of her ART, Ingrid was told that she is not infectious anymore and that, notwithstanding legal concerns, she might have children. She had such a strong desire to have children that it affected her deeply when she was finally able to fulfill that desire: “Ich möchte nicht, dass es esoterisch klingt, aber es hat etwas von Heilwerden, die Möglichkeit jetzt doch noch ein Wunschkind zu bekommen. Auch wenn es zufällig entstanden ist. Das hat etwas von Schmerzlinderung. Es war eine richtige Freude. Diese Kerbe ist jetzt einfach geheilt”. (Ingrid, 75-78). Nonetheless, for a long time she was afraid to transmit the virus to her child, which would have been an umbearable burden. After being impregnated, she suffered “three months of panic” that she might have infected her partner. Unna, who is in a monogamous relationship, stated that the desire for children was a motivation to have sex again and to rely on protection through therapy: “Da war Angst kein Thema. Da war für uns die Absicherung, dass ich ihn eigentlich nicht anstecken kann, wenn ich nicht infektiös bin” (Unna, 153-154). She reported that she received adequate counseling for her and her husband: “Die Medikamente spielen natürlich auch eine Rolle. Wir haben einen guten Arzt, der meinen Mann auch in Behandlung hat und auch regelmäßig testet und der ganz klar sagt, dass wenn man unter der Nachweisgrenze ist, dann ist es mit Sex mit Kondomen vergleichbar” (Unna, 143-146). For Anika a steady relationship or the desire to have children are potential motives to rely on new protection methods: “Ja, wenn der Richtige kommt, auf jeden Fall. Da ist es auch ein Riesenpunkt, zu wissen, dass die Infektiösität praktisch bei Null ist. Sonst würde ich es mich nicht trauen, weil ich nicht damit klar käme, dass ich mein eigenes Kind anstecken könnte” (Anika, 261-263). Ingrid described how she met her husband and how they discussed the plan for another child; eventually deciding against it out of financial reasons and because there were already three children from a former marriage of his. However, in the end Ingrid got pregnant even though they still practiced safer sex with condoms. By that point in 2003, she understood and accepted that there was no risk for the child, but she still had doubts and fears when it came to sex with her partner. She changed her attitude later on during the pregnancy: “Das verrückte ist, im sechsten Monat hatte die Gynäkologin mir gesagt, wenn ich möchte, dann könnte ich spontan gebären. Das habe ich aus Sorge abgelehnt. Ich wäre die dritte Frau in dieser Stadt gewesen. Ich wollte dann doch ganz sicher gehen” (Ingrid, 96-99).

Other couples were informed about the possibility of having sex without condoms, too. For example, Olive expressed her desire to have a child and she and her partner first tried insemination, which did not work. Their next step was to try sex without condoms in combination with pre-exposure prophylaxis (PrEP), however, they were informed about the negative effects of this method. Ultimately, they tried it without condoms and without PrEP: “Ich war dann auf einem Seminar und dort wurde mir gesagt, dass es in unserem Fall, da ich positiv bin und nicht er – anders herum wäre das etwas anderes – und da meine Viruslast unter der Nachweisgrenze liegt und ich regelmäßig Medikamente nehme, brauchen wir uns nicht zu schützen” (Olive, 40-49).

4.2 Comprehensive Description

In this study, non-infectiousness due to an undetectable viral load was examined in the context of the HIV infection and its complex and radical impact on the individual's life. Crucial factors were the severe symptoms of the primary infection, experiences of HIV stigma and the stresses and strains of the HIV regimen, including regular check-ups and adjusting to strong medication. While the infection with HIV is experienced as life changing, the realization of non-infectiousness seemed to be comparably less incisive. All participants seemed more focused on coping with HIV/Aids rather than non-infectiousness.

When the subject of non-infectiousness due to an undetectable viral load was addressed, principally two perceptions were observable: First, the sentiment of not being a danger to others, and second, the impression of regaining a sense of well-being. The former derives from the initial understanding of being contagious and therefore an immediate danger to others, which is increased by the impact of stigmatization, internal stigma and discrimination. The participants expressed feelings of relief and a sense of security in social situations after accepting their non-infectiousness. Consequently, there seemed to be a positive influence on the reduction of internal stigma. Participants were aware of the possibility to perform safer sex without condoms, if both partners agree, the HIV-positive partner is on effective ART, the viral load is undetectable for at least six month, the medication is taken regularly and its effectiveness is checked continuously and neither partners has an STI. This possibility and the willingness to act accordingly indicated an increase in sexual happiness and a decrease of internal stigma.

The feeling of regaining a sense of well-being derived from the desire to lead a normal life in the wake of impending frailty and the awareness of mortality. In this context, an undetectable viral load was synonymous with good health and the reduced viral load numbers led to more vitality and confidence, e.g. in the success of the therapy.

There was a congruent understanding that besides information it takes time to accept non-infectiousness on an individual level, as it is not only a matter of rationality, but also of emotionality. This was due to the complexity of the participants' living situations. Influencing factors were, for example, the difficulty of changing a manifested attitude towards HIV/Aids or the unawareness of the far-reaching implications of non-infectiousness.

Generally, information was lacking on two levels. First, participants experienced a lack of information about non-infectiousness during medical counseling, sometimes only being informed in reply to a question or in the worst case, simply not being informed at all. The participants therefore often relied additionally on other sources like Aids service organizations, public health departments, self-help groups or the Internet. Exceptions were participants with previous knowledge and women who wanted to get pregnant. Second, the lack of information on the current state of scientific knowledge in society resulted in difficulties such as personal conflicts or emotional distress, especially if participants were only recently diagnosed.

Bearing in mind their HIV positive status and an undetectable viral load as well as the option of protection through therapy, participants adjusted their protective behavior to a certain extent. In the wake of the HIV infection, the relevance of other STIs increased and opened up a new discussion of condom use from the standpoint of non-infectious HIV-positive persons. Furthermore, certain focus points shifted, e.g. more reliance on serosorting and sexual communication, difficulties in HIV-serodiscordant relationships.

Finally, the subject of reproductive health is significant, as the desire to have children was a strong motivation for women to rely on protection through therapy. In this regard, participants appeared to receive adequate medical counseling.

5. Discussion

In this study, HIV-positive people reported on their individual coping with non-infectiousness due to effective medical treatment. The results are primarily applicable for western industrialized countries. Eight central categories associated with the behavioral and emotional impact of ART-related non-infectiousness could be developed during the analysis process. The relevance of HIV non-infectiousness in the context of HIV prevention, as well as quality of life, cannot be understated. Indeed, the results indicate a decrease in internalized stigma, due to less fear of HIV transmission. However, the experience of HIV stigma and the regimen of ART outweigh the individual perception of non-infectiousness. In addition, the feeling of being and staying healthy outweighs the perception of non-infectiousness. Overall, the concept of non-infectiousness is too new in the history of HIV/Aids as a whole to fully comprehend yet and it stands in contrast to previous prevention messages that strictly recommended condom use for the past 30 years. These circumstances in addition to potential biases towards, for example, procreative as opposed to recreational sex, lead to a lack of information in the medical setting. The findings in this study indicate that women who wanted children received adequate information about non-infectiousness sooner as opposed to other participants.

Certain aspects in my initial research on this topic were underrepresented in the personal narrations, specifically the discussion about the pressure to begin therapy. This is an important topic, but in this context it was not a predominant issue for the persons interviewed. In addition, findings related to coping with the actual HIV infection were in line with current research on this topic, such as denial, avoidance or self-medication as maladaptive and positive reinterpretation as adaptive coping strategies.

5.1 HIV Infection, Stigma and Regimen of ART

Factors like coping with HIV stigma and the regimen of ART outweighed the perception of non-infectiousness. As described by Baumgartner (Baumgartner 2009, p. 1738), adjusting to living with HIV can be a life-changing period that proceeds in status passages and the HIV diagnosis can result in involuntary, irreversible and undesirable role and identity changes. The interviewees recounted various difficult and challenging experiences (cf. Chapter 4.1.1) and at the time of the interviews basically all participants were still trying to cope with their HIV infection in one way or another, irrespective of the year of positive HIV testing. Coping with HIV stigma, HIV-related lifestyle changes and the HIV regimen with regular check-ups, medication and possible side effects were day-to-day concerns (cf. Chapters 4.1.2; 4.1.3). One third of all participants mentioned a struggle with medical side effects and a subsequent change of medication.

The participants suffered from other hardships in addition to their HIV positive status. Among the 17 narrations, other life circumstances that were reported include job loss, relationship break-up, divorce, difficult family interactions, death of a partner, sexual stigma, addiction, depression, post-traumatic stress disorder from sexual violence, and relocation to a new city. Three women stated that they were diagnosed with HIV during pregnancy, while two of them suffered a miscarriage. For all of them, worries during pregnancy or subsequent grief overshadowed the HIV coping process and accepting non-infectiousness.

While dealing with the consequences of their infection, for some participants an undetectable viral load mainly symbolized the success and effectiveness of the medical drugs and a regained sense of well-being. This can be explained in regard to the physical frailty or the individual distress and psychological helplessness that some participants experienced after the initial infection. This reaction dominated some participants' perception (cf. Chapters 4.3.1; 4.3.2).

In terms of stigma reduction it is important to consider the public awareness of this subject, as the picture of HIV in western industrialized countries needs to shift towards a more rational perception. Knowledge, experience and social interaction are essential for a lasting change. The lack of awareness of ART-induced non-infectiousness in society became clear, as participants were often confronted with situations in which they had to give information on the current state of scientific knowledge about HIV/Aids to others (cf. Chapter 4.6). In some situations, this resulted in societal role conflicts or the feeling of having to justify oneself. Two participants from the United States reported on stronger stigma in their country of origin, and for one of them relocating to Germany allowed him to open up about his HIV status and cope with his situation constructively. This is a positive signal in an otherwise difficult situation. Other cultural differences were observable, such as the varying degree of legal considerations on HIV transmission (cf. p. 69).

5.2 The Emerging Concept of Non-Infectiousness

In the overall history of the HIV/Aids epidemic, the concept of ART-related non-infectiousness is essential for all participants, yet knowledge about long-term experience with an undetectable viral load is still being discovered - on the individual as well as on the societal level. This also refers to long-term experiences with HIV medication, which was addressed and regarded by some participants with worry. Several participants did not go into detail about ART-related non-infectiousness and rather talked vaguely about the facts and background. Concerning one person with even a medical background, a certain detachment was observable, which could derive from doubts about the subject. A cautious response was also observed in a previous study (Persson 2010, p. 1490). When challenged to explain their non-infectious status to others, some participants reported to use likelihoods of HIV transmission as opposed to a specific discourse on non-infectiousness (cf. pp. 63-64). It seemed that the participants who were more outgoing about their HIV infection and therefore used to talking about it, for example, in the context of political activism, were those who had easier access to information on this topic and who had more chances to process this information in interactions with others.

The individual ways of coping with non-infectiousness due to an effective ART were diverse. Many participants stated that they did not know about non-infectiousness before they were infected with HIV. Self-reflection, communication, for example with other HIV-positive persons, and maintaining HIV-serodiscordant relationships were all methods in overcoming long held fears about HIV and facing the possibilities afforded by non-infectiousness (cf. Chapter 4.4). One MSM, after the beginning of ART, experienced a newfound sexual liberation when he was 57 years old. For one female participant, the idea of giving natural childbirth was a turning point in understanding and accepting non-infectiousness.

5.3 Questioning the Extent of Information from Practitioners

As is the case with previous studies (Persson 2010, p. 1490; Rojas Castro 2012, p. 1018), a lack of information about ART-related non-infectiousness in a medical setting became apparent, as several participants reported on not having been adequately informed by their physician or having only been informed by request (cf. Chapter 4.5). This could suggest possible biases towards procreational over recreational sex as well as personal judgements on patients' accountability. It could also indicate ambivalence or doubts on the part of medical practitioners concerning non-infectiousness. Participants thus felt it necessary to seek out other sources for information, e.g. the Internet or Aids service organizations like Deutsche AIDS-Hilfe e.V.. Recency of occurrences and current scientific evidences can also be a factor. However, current publications by DAH, for example, clearly recommend informing PLHIV (DAH 2013, p. 5) about non-infectiousness.

In the context of reproductive health, the findings show that informational talks in the medical setting were sufficient from early on. Among female participants, happiness was tied to parenting, which coincides with previous studies concluding that childbearing patterns and reproductive determinants of HIV-positive women stay similar to those in the general population (Fiore 2008, p. 2143; Nöstlinger 2009, p. 9). In this study the desire to have children seemed to be a strong motivation for women to rely on the viral load method (cf. Chapter 4.8). This applied to women in steady relationships as well as singles.

5.4 Reducing Internal Stigma

As mentioned in the Swiss statement and further researched by Persson, the information on reduced infectiousness can relieve the burden of fear of HIV transmission (Vernazza 2008, p. 168; Persson 2010, p. 1489). The findings of this study are in line with this statement. When the participants talked about ART-induced non-infectiousness, it came from a place of relief as one participant summarized: “Das wirkt sich im gesamten System aus. Man hat ein ganz neues Gefühl zu sich selbst oder mit sich selbst” (Elmar, 93-94).

In line with a previous study (Persson 2013, pp. 1075-1076) infectiousness is neither a singular, cohesive experience, nor is the shift from a dangerous and contagious to a non-infectious HIV corporeality a linear process. Accordingly, every participant individually made sense of the information from the Swiss statement, considering his or her own life circumstances (cf. 4.2.2). Acceptance of the undetectable viral load and its impact was evident in all interviews. However, in most cases this was preceded by time-consuming intellectual and emotional process, unique to each participant (cf. Chapter 4.4).

The impact of HIV stigma on the familial, social, and economic lives of individuals can be devastating. The psychosocial effects of ART-related non-infectiousness, such as an increase in self-esteem, worrying less about being dangerous to others and gaining a feeling of confidence in social interactions, indicate reduced internalized stigmatization (cf. Chapter 4.2.1). In their own words the participants used the following terms and expressions for describing the impact of having an undetectable viral load: “sicherer und zumutbar” (Anika, 139), “einfacher” (Anika, 230), “cool” (Anika, 137), “Lebensqualität” (Unna, 88), “besser in meiner Haut” (Anika, 212), “feel good” (Robert, 175), “Leistungspotential” (Hannes, 49), “Befreiungsmoment” (Hannes, 97), “durchatmen” (Hannes, 98), “selbstsicherer” (Damon, 108), “Heilwerden” (Ingrid, 76), “180 Grad Wendung” (Elmar, 67). As Drewes pointed out (Drewes 2013, p. 3), the level of perceived contagiousness plays a significant role and a reduction of ART-induced contagiousness in combination with a reduction of perceived contagiousness would be necessary to have a lessening effect on HIV stigma.

5.5 Developing Patterns of Sexual Protective Behavior

At heart, information about non-infectiousness was welcomed and accepted and resulted in a new context for sexual protective behavior, more precisely the option of therapy as a protection method. However, this option is not universally embraced. Ten out of the 17 participants sampled for this study, three women and seven men, implicated having had experience with therapy as a protection method in HIV-serodiscordant sex or with a partner of unknown HIV status, some of these experiences being the exception to what they usually practice. One participant was to some degree skeptical of the impact of non-infectiousness, arguing that non-infectiousness alone does not absolve one from consequences (cf. p. 69).

Even though HIV had an obvious impact on people's sex life, it seemed that the basis on which the participants applied protective methods was embedded with more than just the information of being infectious or not. Similar to previous findings (Rojas Castro 2012, p. 1017), little changes in risk behavior were reported. Participants who described high-risk sexual behavior before their positive HIV test result revealed the same tendency afterwards, while other participants maintained a cautious approach (cf. Chapter 4.7.1). In a previous study (Persson 2010, p. 1490), the complex nature of sexual decision-making was emphasized. It is not solely based on information, but much rather shaped by a multitude of influencing factors, such as intimacy dynamics, gender roles, emotions or experiences of stigma. Some participants relied on the undetectable viral load as a protection method for pleasure, some only for the purpose of insemination and others not at all (cf. Chapter 4.7.1). It was evident that in regard to their living situations, needs and character, the participants in this study individually integrated the knowledge about ART-related non-infectiousness into their sex life, however, sexual disinhibition based only on the status of not being infectious was not observable, which is in line with Rojas Castro's study (Rojas Castro 2012, p. 1017).

Persson stated that knowledge about the Swiss statement resulted in an increase in sexual communication. Explicit communication, sexual education and risk calculation are essential elements for successful protective behavior and were also addressed in the interviews. The possibility of condomless sex brought up the question of responsibility, as mentioned in the Fernández-Dávila study (Fernández-Dávila 2013, p. 367). Condoms were mentioned as being used not only during serodiscordant sex, but also as a way to avoid further STI transmission, mostly referring to Hepatitis C (cf. Chapter 4.7.3). Contradictory statements regarding consistency of condom use arose possibly due to a social desirability bias.

In the context of serosorting, more common among MSM, the assurance that both partners are taking medication and undergoing regular check-ups reduces worries of HIV or STI transmission (cf. Chapter 4.7.2), as one participants said: "Ich hatte auch noch keinen Fall, wo jemand positiv war und nicht in Therapie war. Ich weiß nicht, ob das nochmal einen Unterschied machen würde" (Enzo, 267-269). This also indicates the possibility of condom use based upon the viral load level. However, in the 17 interviews no other comments on viral load sorting as opposed to serosorting could be found. It should also be noted that generally, HIV-positive men who serosort risk higher rates of STIs, which may lead to a higher viral load and increased chances of transmitting HIV to other sex partners. Considering viral blips, studies have shown that viral loads are rarely raised under effective ART and if so, only to a level that does not indicate significant infectiousness. An infection with another HIV genotype could lead to a superinfection, which is associated with complications such as drug resistance and increased virulence. However, in line with current research, a multiple HIV infection appears to occur only rarely (Eaton et al. 2010, p. 3).

5.6 Limits of the Methodology

Certain limitations were encountered in this study. As there was no funding for the research project I could not offer any incentive for the interviewees or travel expenses. Therefore most of the participant recruitment and interview conduction had to be conducted locally. However, one third of the sample were conducted and interviewed during HIV seminars at Akademie Waldschlösschen. These participants were open to share their experience and also had an explicit interest and intention to reflect their HIV-related issues. Ultimately, an incentive could have led to a more diverse sample attracting a wider range of people. The potential types of coping might have been more varied, as people who are generally shy or introverted are probably also less likely to volunteer for a study project. Consequently, there is a bias. For various reasons it turned out to be challenging to reach out to certain groups, for example people from rural areas or people with a non-German background, which includes people from countries with high-prevalence on HIV infection among its citizens. A limited time frame was another obstacle. Considering the interview process, the interviews covered the HIV infection as a starting point. For participants who were still adjusting to their new situation, this might have been an invitation to mainly talk about HIV-related concerns.

6. Outlook

These results offer a framework for future research on this subject. From a Public Health angle, the reduction of HIV transmission and HIV stigma is vital. As an inductive research method, the phenomenological analysis of these interviews offers an insight into potential ways of individual coping with ART-related non-infectiousness, which can contribute to the field of HIV prevention and health promotion. Future research in this area could focus on specific population groups, for example MSM and women. New processes, such as therapy as a protective method, should to be communicated in the public sphere. The field of HIV prevention, with it's long and emotionally charged history, is not a black and white issue. The experiences and living situations of PLHIV and the stresses and possible consequences that are entailed in sexual decision-making are complex. This complexity and the persistent dissonance of this reality should always be considered. HIV stigma is a serious issue with severe consequences for individuals, families and communities. Non-infectiousness has the potential to change the entire discourse on HIV, however, there are still individual and situational variables, as revealed by this study and others, that significantly coincide with this phenomena. There is a need for objective and realistic communication on this matter in the medical setting, as patients should be directly informed equally about the opportunities, risks and possibilities. Still, it must be clear that there is no pressure to begin therapy. Public awareness of this subject should increase, as an open, positive and realistic approach to HIV will prove nothing but beneficial to society as a whole. Furthermore, additional inquiry on the effects of successful ART on HIV stigma and internalized stigmatization is recommended.

Sources

Attia S., Egger, M., Müller, M., Zwahlen, M. & Low N. (2009). *Sexual transmission of HIV according to viral load and antiretroviral therapy: systematic review and meta-analysis.*. AIDS; 23(11):1397-1404.

Bartha I., Jin, F., Prestage, G., Zablotska, I., Koelsch, K.K., Phanuphak, N. Grinsztejn, B., Cooper, D.A., Fairley, C., Kelleher, A., Triffitt, K. & Grulich, A.E. (2013). *Superinfection with drug-resistant HIV is rare and does not contribute substantially to therapy failure in a large European cohort.* BMC Infectious Diseases; 13:537.

Baumgartner, L.M. (2007). *The Incorporation of the HIV/AIDS Identity Into the Self Over Time.* Qual. Health Res.; 17:919-931.

Baumgartner L.M. & Keegan D.N. (2009). *Accepting Being Poz: The Incorporation of the HIV Identity Into the Self. Qual. Health Res.;* 19:1730-1743.

Bavinton, B.R. Jin, F., Prestage, G., Zablotska, I., Koelsch, K.K., Phanuphak, N. Grinsztejn, B., Cooper, D.A., Fairley, C., Kelleher, A., Triffitt, K. & Grulich, A.E. (2014). *The Opposites Attract Study of viral load, HIV treatment and HIV transmission in serodiscordant homosexual male couples: design and methods. BMC Public Health; 13:917*.

Berg Rigmor C. & Ross Michael W. (2014). *The Second Closet: A Qualitative Study of HIV Stigma Among Seropositive Gay Men in a Southern U.S. City*. International Journal of Sexual Health; 26(3):186-199.

Block, R.G. (2009). *Is It Just Me? Experiences of HIV-Related Stigma.* Journal of HIV/AIDS & Social Services; 8:1-19.

Bochow, M., Lenuweit, S., Sekuler, T. & Schmidt, A.J. (2010). *Schwule Männer und HIV/Aids: Lebensstile, Sex, Schutz- und Risikoverhalten.* Berlin: Deutsche AIDS-Hilfe e.V.

Bryman, A. (2012). How many qualitative interviews is enough? In: E. Baker & R. Edwards (Eds.). *How many qualitative interviews is enough? Expert voices and early career reflections on sampling and cases in qualitative research* (pp. 18-20). Southhampton: National Centre for research methods.

Carter M. & Hughson, G. (2014). *Viral Load.* Accessible at: http://www.aidsmap.com/Viral-load/page/1044622/#item1044625. [24.10.2014]

CHIP (2014). *The PARTNER Study – stage 2 (2014-2017): Estimating the risk of HIV transmission irrespective of sexual practice.* Accessible at: http://www.cphiv.dk/portals/0/files/PARTNER2.pdf. [24.10.2014]

Cohen M.S., McCauley, M. & Gamble, T.R. (2011). *HIV treatment as prevention and HPTN 052.* Current Opinion in HIV & AIDS; 7(2):99-105.

Creswell, J.W. (2013). *Qualitative inquiry and research design: Choosing among five approaches.* (3rd ed.). Thousand Oaks: Sage Publications.

Crocker, J., Major, B & Steele, C. (1998). Social Stigma. In: D.T. Gilbert, S.T. Fiske, G. Lindzey (Eds.). *Handbook of Social Psychology* (4th ed., Vol. 2, pp. 504-553). New York: McGraw-Hill.

Del Romero J., Castilla, J., Hernando, V., Rodriguez, C. & García, S. (2010). *Combined antiretroviral treatment and heterosexual transmission of HIV-1: cross sectional and prospective cohort study.* BMJ; 340:c2205.

Deutsche AIDS-Hilfe e.V. (2009). *HIV-Therapie und Prävention.* Positionspapier der Deutschen AIDS-Hilfe e.V. (DAH). Accessible at: http://www.aidshilfe.de/de/aktuelles/meldungen/positionspapier-hiv-therapie-und-praevention. [24.10.2014]

Deutsche AIDS-Hilfe e.V. (2013). *Schutz durch Therapie ist Safer Sex.* Positionspapier der Deutschen AIDS-Hilfe e.V. (DAH). Accessible at: http://www.aidshilfe.de/sites/default/files/201110%20Positionspapier%20Schutz%20durch%20Therapie_1.pdf. [24.10.2014]

Deutsche AIDS-Hilfe e.V. (2014a). *Strafrecht.* Accessible at: http://www.aidshilfe.de/de/leben-mit-hiv/recht/strafrecht?page=1. [24.10.2014]

Deutsche AIDS-Hilfe e.V. (2014b). *"positive stimmen - Ergebnisbericht des PLHIV Stigma Index in Deutschland.* Accessible at: http://www.aidshilfe.de/sites/default/files/positive%20stimmen%20Ergebnisbericht.pdf. [24.10.2014]

Dresing, T. & Pehl, T. (2012). *Praxisbuch Interview & Transkription. Regelsysteme und Anleitungen für qualitative ForscherInnen.* (4th ed). Marburg: Eigenverlag.

Drewes, J. & Kleiber, D. (2014). *Contagiousness under antiretroviral therapy and stigmatization toward people with HIV*. AIDS Care; 26(11):1383-1386.

Eaton, L.A., Kalichman, S.C., O'Connell, D.A. & Karchner, W.D. (2010). *A strategy for selecting sexual partners believed to pose little/no risks for HIV: Serosorting and its implications for HIV transmission.* AIDS Care; 21(10):1279-1288.

European AIDS Treatment Group (2014). *Community consensus statement on the use of antiretroviral therapy in preventing HIV transmission.* Accessible at: http://www.hivt4p.org/wp-content/uploads/2014/02/Community-consensus-statement-with-appendices-and-references.pdf. [24.10.2014]

Fernández-Dávila, P. & Carmona A.M. (2013) *Discursos Sobre La Responsabilidad Sexual En Hombres VIH-positivos Que Tienen Sexo Con Hombres,* Rev Esp Salud Pública; 87:367-382.

Fiore, S., Heard, I., Thorne, C., Savasi, V., Coll, O., Malyuta. R., Niemiec, T., Martinelli, P., Tibaldi, C. & Newell, M.-L. (2008). *Reproductive experience of HIV-infected women living in Europe.* Hum. Reprod.; 23(9):2140-2144.

Flick, U. (2012). *Qualitative Sozialforschung. Eine Einführung* (5th ed.). Reinbek: Rowohlt.

Garnett G.P. & Gazzard B. (2008). *Risk of HIV transmission in discordant couples.* The Lancet, 372(9635):270-271.

Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. New York: Simon & Schuster.

Herek, G.M. & Capitanio, J.P. (1998). *Symbolic Prejudice or Fear of Infection? A Functional Analysis of AIDS-Related Stigma Among Heterosexual Adults.* Basic and Applied Social Psychology, 20(3):230-241.

Hopf, C. (2012). Qualitative Interviews - ein Überblick. In: U. Flick, E. von Kardorff, I. Steinke (Eds.). *Qualitative Forschung. Ein Handbuch* (9th ed., pp. 349-359). Reinbek: Rowohlt.

Kuzoe-Liengme B. & Hirschel B. & Schiffer V. (2010). *Swiss statements: a two-year follow-up. Rev Med Suisse.* 6(243):714-718, 720.

Kowal, S. & O'Connell, D.C. (2012). Zur Transkription von Gesprächen. In: U. Flick, E. von Kardorff, I. Steinke (Eds.). *Qualitative Forschung. Ein Handbuch* (9th ed., pp. 437-446). Reinbek: Rowohlt.

Lamnek, S. (2010). *Qualitative Sozialforschung. Lehrbuch.* (5th rev. ed.). Weinheim/Basel: Beltz.

Lewis J. (1999) *Status Passages.* Journal of Homosexuality; 37(3):87-115.

Link, B.G. & Phelan, J.C. (2001). *Conceptualizing Stigma.* Annu. Rev. Sociol.; 27:363-85.

Mahajan, A.P., Sayles, J.N., Patel, V.A., Remien, R.H., Sawires, S.R., Ortiz, D.J., Szekeres, G. & Coates T.J. (2008). *Stigma in the HIV/AIDS epidemic: A review of the literature and recommendations for the way forward.* AIDS; 22(2):67-79.

van Manen, M. (1990). *Researching Lived Experience. Human science for an action sensitive pedagogy*. Albany, New York: State University of New York Press.

Major, B. & O'Brien, L.T. (2005). *The Social Psychology Of Stigma.* Annu. Rev. Psychol.; 56:393-421.

Marcus, U., Schmidt, A.J. & Hamouda, O. (2011). HIV *Serosorting among HIV-positive men who have sex with men is associated with increased self-reported incidence of bacterial sexually transmissible infections.* Sexual Health; 8(2):184-193.

Merkens, H. (2012). Auswahlverfahren, Sampling, Fallkonstruktion. In: U. Flick, E. von Kardorff, I. Steinke (Eds.). *Qualitative Forschung. Ein Handbuch* (9th ed., pp. 286-298). Reinbek: Rowohlt.

Nöstlinger, C.M., Nideröst, S., Woo, R., Platteau, T., Loos, J. & Colebunders, R. (2010). *Aidsimpact Special Issue: Mirror, Mirror on the Wall: The Face of HIV+ Women in Europe Today.* AIDS Care; 22(08):919-926.

Persson A. (2008) Sero-silence and sero-sharing: managing HIV in serodiscordant heterosexual relationships. AIDS Care; 20(4):503-506.

Persson A. (2010) *Reflections on the Swiss Consensus Statement in the context of qualitative interviews with heterosexuals living with HIV.* AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV; 22(12):1487-1492.

Persson, A. (2013), *Non/infectious corporealities: tensions in the biomedical era of "HIV normalization".* Sociology of Health & Illness; 35(7):1065-1079.

Robert Koch-Institut (2012). *HIV/AIDS in Deutschland. Eckdaten der Schätzung*. Accessible at: http://www.rki.de/DE/Content/InfAZ/H/HIVAIDS/Epidemiologie/Daten_und_Berichte/EckdatenDeutschland.pdf?__blob=publicationFile. [04.12.2014]

Rodger, A., Bruun, T., Weait, M., Vernazza, P., Collins, S., Estrada, V., Van Lunzen, J., Corbelli, G.M., Lampe, F., Phillips, A. & Lundgren, J. (2012). *Partners of people on ART – a New Evaluation of the Risks (The PARTNER study): design and methods.* BMC Public Health; 12(296):1-6.

Rodger, A., Bruun, T., Cambiano, V. & Lundgren, J. (2014). *HIV Transmission Risk Through Condomless Sex If HIV+ Partner On Suppressive ART: PARTNER Study.* Conference on Retroviruses and Opportunistic Infections (CROI 2014). Boston, March 3-6. Abstract 153LB. Accessible at: http://www.hivandhepatitis.com/hiv-prevention/hiv-test-treat/4553-croi-2014-no-one-with-undetectable-viral-load-transmits-hiv-in-partner-study. [24.10.2014]

Rojas Castro D., Fugon, L., Bourgeois-Fisson, E., le Gall, J.M., Barbier, F. & Spire, B. (2012) *The "Swiss Statement": Who knows about it? How do they know? What are its effects on people living with HIV/AIDS?.* AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV; 24(8):1013-1019.

Sanjuán P. (2013). *Coping with HIV Related Stigma and Well-Being.* J Happiness Stud.;14:709-722

Santos-Hövener, C., Zimmermann, R., Kücherer, C., Bätzing-Feigenbaum, J., Wildner, S., Hamouda, O. & Marcus, U. (2014). *Conversation about Serostatus decreases risk of acquiring HIV: results from a case control study comparing MSM with recent HIV infection and HIV negative controls.* BMC Public Health; 14:453.

Smit, P.J., Brady, M., Carter, M., Fernandes, R., Lamore, L., Meulbroek, M., Ohayon, M., Platteau, T., Rehberg, P., Rockstroh, J.K. & Thompson, M. (2011). *HIV-related stigma within communities of gay men: a literature review.* AIDS Care; 24(4):405-412.

Smith, M.D., Richman, D.D. & Little, S.J. (2005). *HIV Superinfection.* J Infect Dis.; 192(3):438-444.

Vernazza P., Hirschel, B., Bernasconi, E. & Flepp, M. (2008). *HIV-infizierte Menschen ohne andere STD sind unter wirksamer antiretroviraler Therapie sexuell nicht infektiös.* Schweizerische Ärztezeitung; 89(5):165-169.

Appendices

The appendices contain the following documents:

- Interview Guideline
- Sociodemographical Data
- Questionnaire on Biographical Data
- Informed Consent Document
- Time Table

Appendix A. Interview Guideline

Hochschule für Angewandte Wissenschaften Hamburg
Hamburg University of Applied Sciences

Deutsche AIDS-Hilfe

Interviewleitfaden

In meinem Projekt gehe ich der Frage nach der Verarbeitung der HIV-Infektion und dem Umgang mit der Nichtinfektiösität nach.

In dem Interview geht es um Deine persönliche Geschichte – Deine Erlebnisse, Gedanken und Gefühle. Dies ist ein offenes Interview!

Das positive HIV-Testergebnis!

Wie ging es weiter?

Wann hast du mit der ART angefangen?

Welche Veränderungen gab es und wie war der Verlauf?

Soziales Umfeld!

Freunde, Bekannte, Arbeitsplatz, Partner – Reaktionen?

Sexualität – Veränderungen?

Infektiösität?

Sexuelle Zufriedenheit?

Appendix B. Sociodemographic Data

No.	Name	Gender	Age	Country of origin	Year of Positive HIV testing	Year of ART beginning
#01	Nicola	female	49	DE	2000, PEP not successful	2000
#02	Unna	female	n/a	DE	2010, during pregnancy	2010
#03	Anika	female	n/a	DE	2006, medical state exam	2010
#04	Urs	male	37	DE	2009	2009
#05	Hannes	male	65	DE	1997	1999
#06	Damon	male	31	DE	2011	2011
#07	Ingrid	female	48	CH	1994, miscarriage	1999
#08	Till	male	32	DE	2013	2013
#09	Enzo	male	46	DE	2013	2013
#10	Elmar	male	57	DE	2006	2013
#11	Ansgar	male	35	DE	2005	2007
#12	Hagen	male	36	DE	2004	2005
#13	Robert	male	30	US	2005, PEP not successful	2012
#14	Andrew	male	30	US	2011	2011
#15	Olive	female	n/a	CM	2008, miscarriage	2009
#16	Alex	male	51	TG	2007	2008
#17	Collin	male	34	LU	2011	2012

No.	Occupational and Social Background	Family and Partner Status	Serodiscordant sex without condoms
#01	Nurse, HIV research, political activist, 12 years in Africa	Serodiscordant relationship	No
#02	Housewife	Serodiscordant marriage, mother	Yes
#03	Physician, development aid	Single	No
#04	Freelance medical representative	Seroconcordant relationship	No
#05	Technician at broadcasting studio, since 1998 pensioner	Single	Yes
#06	Cosmetician and make-up artist, project manager	Seroconcordant relationship	Yes
#07	Political activist	Serodiscordant relationship, mother	Yes
#08	University degree, barkeeper	Single	Yes
#09	Teacher	Seroconcordant relationship	No
#10	Editorial journalist, freelancer	Single	No
#11	Male nurse, hospice, University degree	Single	No
#12	Graduated pedagogue	Seroconcordant relationship	Yes
#13	In Germany since 2008, party promoter, student	Single	Yes
#14	In Germany since 2012	Seroconcordant relationship	Yes
#15	In Germany since 1997	Serodiscordant relationship, mother	Yes
#16	In Germany since 1990, stock management in logistics industry	Serodiscordant marriage, living apart, father	No
#17	In Germany since 2008, University degree, tailor	Single	Yes

Appendix C. Questionnaire on Biographical Data

Hochschule für Angewandte Wissenschaften Hamburg
Hamburg University of Applied Sciences

Deutsche AIDS-Hilfe

Biografischer Datenbogen

Qualitative Forschungsarbeit zur individuellen Verarbeitung und zum Umgang von HIV-positiver Männer und Frauen mit der Nichtinfektiösität bei erfolgreicher ART

Wohnort:______________________________

Alter:______________________________

Geschlecht:______________________________

Nationalität:______________________________

höchster Bildungsabschluss:________________________

Gelernter Beruf: ____________________________

derzeitige berufliche Tätigkeit:________________________

Jahr der HIV-Diagnose:__________________________

Beginn der ART:____________________________

nur vom Interviewer auszufüllen:

Datum:
Ort:
Dauer:

Appendix D. Informed Consent Document

Hochschule für Angewandte Wissenschaften Hamburg
Hamburg University of Applied Sciences

Deutsche
AIDS-Hilfe

Einverständniserklärung und Datenschutzvereinbarung

Sehr geehrte(r) Frau / Herr …..,

ich danke herzlich für die Bereitschaft am Interview zum Thema „Individuelle Verarbeitung und Umgang mit der „Nichtinfektiösität" HIV-positiver Männer und Frauen bei ART-supprimierter Virämie" teilzunehmen.

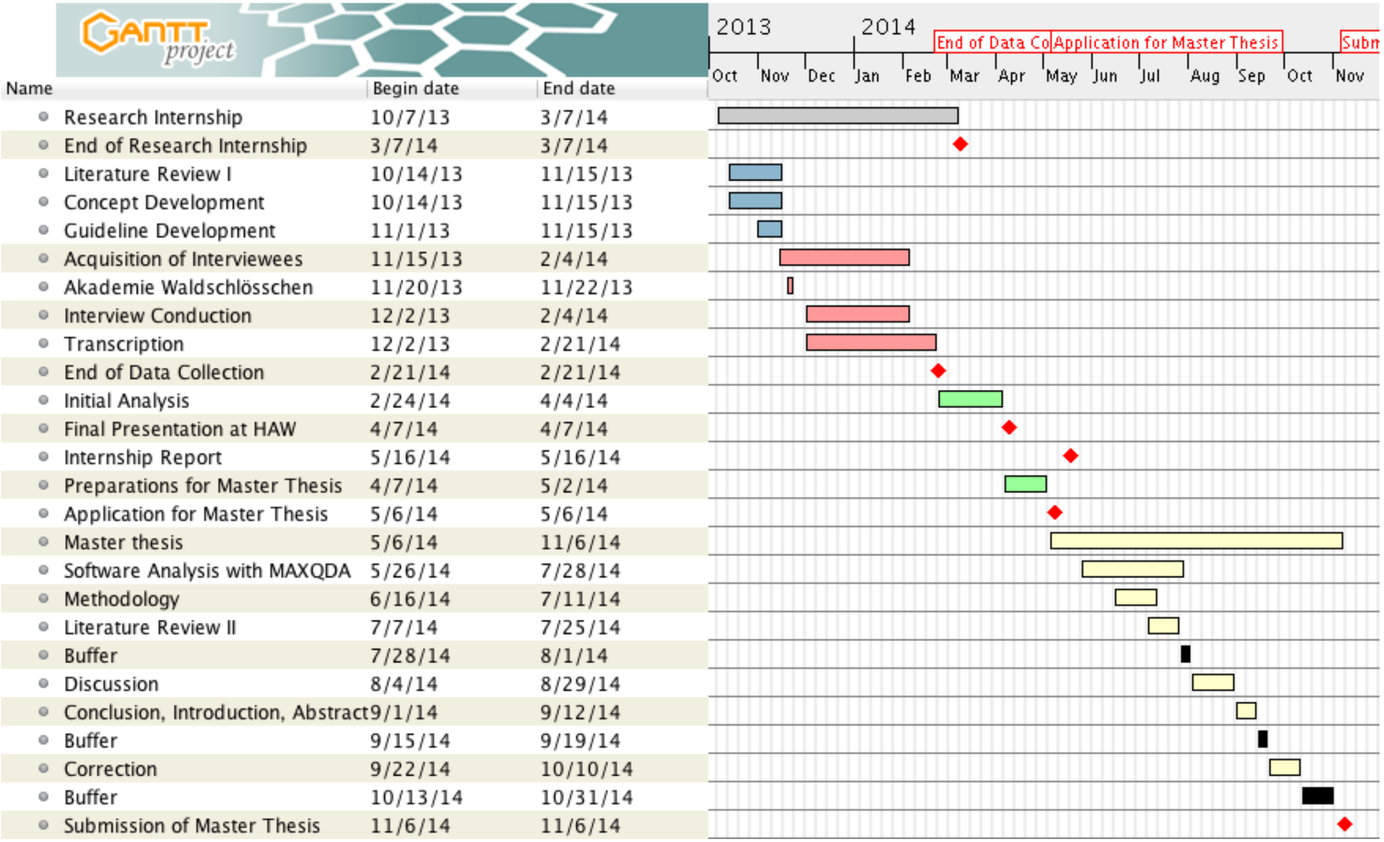
Mit dieser Vereinbarung gestatten Sie, das Interviewmaterial im Rahmen dieser Forschungsarbeit der Deutschen AIDS-Hilfe und der Hochschule für angewandte Wissenschaften in Hamburg (HAW) zu verwenden. Es wird nur für diese Zwecke verwendet und bleibt komplett anonym.

1. Die Teilnahme ist freiwillig.
2. Der Interviewte hat das Recht, Fragen unbeantwortet zu lassen.
3. Das Interview ist Teil einer empirischen Untersuchung im Rahmen einer Abschlussarbeit. Die Daten aus dem Interview werden ganz oder teilweise verschriftlicht. Das aufgezeichnete Interview wird danach sofort gelöscht.
4. Anonymität wird zugesichert.
   (Rückschlüsse auf einzelne Personen werden nicht möglich sein. Namen und Adressen werden nicht erhoben. Zitate werden nicht persönlich gekennzeichnet.)

……..…...	....
Interviewpartner	Interviewer

Beide Parteien erhalten eine Ausfertigung dieser Vereinbarung.

Appendix E. Time Table



Name	Begin date	End date
Research Internship	10/7/13	3/7/14
End of Research Internship	3/7/14	3/7/14
Literature Review I	10/14/13	11/15/13
Concept Development	10/14/13	11/15/13
Guideline Development	11/1/13	11/15/13
Acquisition of Interviewees	11/15/13	2/4/14
Akademie Waldschlösschen	11/20/13	11/22/13
Interview Conduction	12/2/13	2/4/14
Transcription	12/2/13	2/21/14
End of Data Collection	2/21/14	2/21/14
Initial Analysis	2/24/14	4/4/14
Final Presentation at HAW	4/7/14	4/7/14
Internship Report	5/16/14	5/16/14
Preparations for Master Thesis	4/7/14	5/2/14
Application for Master Thesis	5/6/14	5/6/14
Master thesis	5/6/14	11/6/14
Software Analysis with MAXQDA	5/26/14	7/28/14
Methodology	6/16/14	7/11/14
Literature Review II	7/7/14	7/25/14
Buffer	7/28/14	8/1/14
Discussion	8/4/14	8/29/14
Conclusion, Introduction, Abstract	9/1/14	9/12/14
Buffer	9/15/14	9/19/14
Correction	9/22/14	10/10/14
Buffer	10/13/14	10/31/14
Submission of Master Thesis	11/6/14	11/6/14

Declaration of Independent Work

I hereby confirm that I am the author of the thesis presented. I have written the thesis as applied for previously unassisted by others, using only the sources and references stated in the text.

Place, Date

Signature, Björn Trenker