

Acknowledgements

This thesis could never have materialised if it had not been for the following people – whom I am forever grateful.

Thank you to Tinne Laursen at Aarhus University Hospital Skejby for giving me the opportunity to experience the activities and the very special atmosphere in connection with the Youth Group. I am grateful for the work and effort both you and Lotte Rodkjær contributed in regards to finding informants, informing about relevant events in connection with HIV and for being positive, friendly and welcoming.

I am very pleased to have had great informants - you have all contributed to the empirical data which was necessary for this thesis. Experiencing how you handle being HIV-positive has been an eye-opener and an inspiration. Your attitude, willpower and courage are commendable. Thank you for being open and honest about your everyday lives.

I also wish to thank my advisor Astrid Pernille Jespersen for constructive and critical advice, alongside encouragement!

A few others have to be mentioned because they have also been a great help:

Amy: Thank you for proof reading, I know that this thesis would not have been the same without your help. Writing in a foreign language has taught me to be very humble in that respect and I admire your skills.

Jim: (my dad): Thank you for always volunteering to help – I appreciate it. Thanks to both you and Lisbeth, (my mom), for being so much fun and for believing in me.

Lene: Thank you for making a beautiful front page and style sheet.

Anna: Thank you for all the extra commas you have added.

Nikolaj Darre: Thank you for good company and interesting conversations.

To all other friends and fellow thesis writers whom I have shared this experience with: Thank you for great talks and lots of coffee along the way.

Resumé

Forskellige versioner af HIV - en analyse af hvordan unge mennesker i Danmark performer en kronisk sygdom.

Nærværende speciale undersøger, hvordan HIV performs af unge HIV-smittede i Danmark. Specialet indskriver sig i et bestemt teoretisk felt, hvor praksis er omdrejningspunktet. Herigennem bliver HIV en sygdom, som træder frem, skabes og performs i forskellige versioner. Specialets empiriske materiale er baseret på feltarbejde, som blev udført i perioden august 2010 til april 2011. Specialet er desuden resultatet af et samarbejde med Ungegruppen, som har til huse på Århus Universitetshospital, Skejby. De fem anvendte informanter er i dag i aldersgruppen 25 til 28 år. De blev smittet med HIV, da de var mellem 17 og 22 år, og fælles for alle fem informanter er, at de deltager aktivt i Ungegruppen.

Med udgangspunkt i denne specifikke gruppe af informanter undersøges, hvordan HIV påvirker de unges hverdagspraksis, samt hvordan de håndterer at leve med denne kroniske sygdom. Med ordet performer indskriver specialet sig i en bestemt teoretisk retning, som definerer sygdomme som multiple og dermed eksisterende i forskellige versioner. HIV skal derfor analyseres ud fra de forskellige praksisser, den indgår i. En praksis er kendetegnet ved at være afhængig af, hvor og hvordan den udspiller sig, formes e.i. gøres. Hos den praktiserende læge, i forbindelse med bloddonation og i laboratoriet er derfor tre forskellige versioner af HIV. I disse versioner enacts HIV bl.a. i en konsultation med udgangspunkt i en syg patient. Hos den praktiserende læge underlægges patienten en fysisk undersøgelse og et interview, og hvis den praktiserende læge ikke kan finde et svar på de symptomer, som patienten beskriver, sendes patienten videre til andre undersøgelser. Denne teoretiske tilgang overskrider dikotomien mellem illness og disease, hvor illness betegner og undersøger patientens perspektiv, hvorimod disease er det medicinske perspektiv. I en performativ tilgang er dette udgangspunkt en søgen væk fra det objekt, man undersøger (HIV), hvor objektet forbliver uberørt. Med udgangspunkt i praksis skabes HIV i mange forskellige men forbunde versioner, som udspilles i praksis.

Analysen falder i tre forskellige dele, hvor den første fokuserer på, hvordan HIV gøres i forbindelse med behandlingen af sygdommen. Denne del beskriver, gennem de forskellige versioner, hvordan de unge HIV-smittede oplevede at blive diagnosticeret med HIV, samt hvordan de efterfølgende håndterer medicinering og ændringer i behandlingen. Dermed understreges det ”arbejde”, som kroniske patienter udfører i forbindelse med deres sygdom.

Anden del af analysen flytter fokus til, hvordan de unge HIV-smittede performer HIV i deres sociale liv i forhold til kærester, venner og familie. I denne del udpeges tre forskellige idealtyper: tavshed, åbenhed og karma. Hver idealtipe er et sammendrag af karakteristiske træk fra det empiriske materiale, diskurser, historier og fortællinger, og herigennem kan de tre idealtyper anvendes til at udpege mønstre, som former de måder, hvorpå det sociale organiseres. Dette kombineres med frygten for at blive stigmatiseret og afvist af andre mennesker.

Tredje del tager udgangspunkt i Ungegruppens årlige weekendtur og analyserer, hvordan de unge efter at have deltaget i weekendturen har erhvervet sig nye kompetencer og evner i forbindelse med at leve med HIV. De unge bliver i kraft af aktiviteterne og rammerne for weekendturen i stand til at se HIV som en gave; som noget positivt.

Som helhed undersøger specialet forskellige versioner af HIV i en dansk kontekst med udgangspunkt i unge HIV-smittede. Dette understreger de mangfoldige måder, hvorpå HIV påvirker de unges

hverdagsliv både i forbindelse med diagnose, behandling og i deres sociale liv - samt gennem Ungegruppen. Dermed bidrager specialet med indsigt i, hvordan HIV påvirker en bestemt gruppe af patienter.

Table of contents

Acknowledgements.....	01
Resumé (summary in Danish).....	02
Prologue.....	06
Chapter 1 Introduction.....	08
Empirical data.....	09
Language.....	09
Problem definition.....	09
Theoretical inspiration.....	10
Applicability.....	11
Structure.....	11
About method.....	12
About the informants.....	13
Empirical data.....	13
Access.....	13
Re-negotiation.....	14
The location of the field.....	14
Choosing a topic.....	15
Insider or outsider?.....	15
An ethnologic design game.....	16
Interview.....	18
Chapter 2 Theoretical foundation.....	19
The performative turn.....	19
Perspectivalism.....	19
Diagnosis.....	21
Another version.....	22
Detection of HIV.....	23
Feeling at risk.....	23
The patient past and present.....	24
Clinical version.....	25
Room for more.....	27
CD4 count.....	28
Double-edged sword.....	28
Being on medication.....	29
A partnership for life.....	30
The ultimate solution.....	31
Summary.....	31
Chapter 3 Stigma and social ordering.....	33
Erving Goffman.....	33
Identity.....	33
Stigma.....	34
Modes of ordering.....	35

Three modes of ordering.....	36
Exploring stigma and modes of ordering.....	37
Openness.....	38
Silence: caught in a spider web.....	39
Silence: a great liar.....	39
Relationships and one-night stands.....	40
Karma.....	42
Summary.....	43
Chapter 4 HIV a gift ?.....	44
Surprised by Methadone.....	44
A dispositif.....	45
The Youth Group.....	46
Generous constraints.....	46
Warrior or Victim?.....	47
The weekend trip.....	48
Arrival.....	48
Trust.....	48
Life experiences.....	49
Change.....	50
A session with Hawk.....	50
Pleased about HIV.....	51
Hello, HIV cannot be a gift.....	52
Being a warrior.....	52
Waiting a whole year.....	53
Summary.....	54
Conclusion.....	55

Prologue

In the early 1980s, a prestigious medical journal¹ discussed the large number of male patients who were presenting with symptoms that suggested they were immunodeficient, yet no known cause for their symptoms could be found. A common denominator for these patients was their homosexuality; the new disease was therefore perceived as infecting *only* homosexual men. This was illustrated by one of its first names: Gay Related Immune Deficiency (GRID) (Epstein 1996: 50). The initial understanding of the disease was that it only infected gay men, and it was explained by and linked to “the gay way of life” (ibid.: 51), but soon other risk groups were defined. First, intravenous drug addicts and prostitutes were added; heterosexuals were included later when physicians established that the disease spread through sexual contact (Nielsen 1994: 17). By 1982, the disease became known as Acquired Immune Deficiency Syndrome or AIDS.² The disease was further explored, and the cause was found: Human Immunodeficiency Virus or HIV (ibid.).³ At the time when AIDS and HIV were first identified, almost all contagious diseases were treatable and therefore not perceived to be hazardous threats; rather, they were diseases that medical science was able to control and cure (at least in the Scandinavian countries). But in that respect, AIDS changed medical confidence because finding a cure – or at least a treatment – was much harder than expected. The initial lack of knowledge about HIV and AIDS, combined with the means of transmission, created great fear of an epidemic and an increased focus on sexual behaviour, especially casual sex. This became palpable in the public debates in Denmark when newspaper articles stated that both gay men and prostitutes were likely to spread the disease to the rest of the population, which would result in an epidemic. This fear was reflected in the prevention schemes that were launched (Vallgård 2003: 246; Matic 2006: 2). The National Board of Health⁴ initiated a prevention scheme in the mid-1980s, and a brochure was distributed to *all* households in Denmark, which reflected the fear of a national epidemic (ibid.; Nielsen 1994: 18-21). Starting in 1987, treatment for HIV and AIDS gradually became available. However, it was not until 1996 that a combination of different kinds of medicine became widely available in many Western countries; with the use of this, HIV changed from a deadly disease to a chronic one (Matic 2006: 1).

By describing the initial understandings of AIDS and HIV, it is possible to position this thesis in its historical context. Since AIDS and HIV were first identified, there have been many changes in treatment, and this thesis centres on HIV as a chronic disease that requires medication to be available to patients. The thesis takes another step by focusing on a particular group of people with HIV (known as “HIV-positive”); specifically, young people in Denmark. The point of departure is this group of patients and how their everyday lives are affected by being diagnosed with HIV. A third step is necessary to “set the stage”, which is concerned with describing and analysing HIV as a single disease; therefore, I claim that HIV should not be described and analysed as single, but should rather be viewed

¹ *The New England Journal of Medicine* (Gazzard & Jones 2006: 101).

² AIDS: Acquired Immuno Deficiency Syndrome: “a person is diagnosed with AIDS when certain infections appear. These infections include a certain type of pneumonia that only occurs when the immune system is weakened. In this condition, HIV has destroyed so many helper T-cells that the immune system no longer responds properly to the frequent small and large attacks to the immune system” (Kehlet 2006: 74).

³ HIV: Human Immunodeficiency Virus. When a person is infected the virus “slowly starts to destroy the immune system. HIV attacks live cells to take advantage of their metabolism. HIV specifically attacks some of the white blood cells that play an important role in the immune system. These are called helper T-cells or CD4 cells. In most cases, it takes years before the number of helper T-cells is so low that the immune system no longer functions properly. Because of the low number of helper T-cells, the immune system cannot carry out its central task of protecting the body from all the other types of viruses and bacteria that surrounds us. (...) The period of time from when a person has been infected with HIV to when the immune system has been weakened varies (...). If you do not receive medical treatment, then on average, 7-9 years go by from the time of infection to when the first serious symptom appears” (ibid.: 74).

⁴ The National Board of Health (Sundhedsstyrelsen) is the governing health care authority in Denmark, which assists the Minister of Interior and Health (<http://www.sst.dk/English.aspx>).

as multiple. These three steps correlate to the title of the thesis: *Different versions of HIV– an analysis of how young people in Denmark perform a chronic disease*, which is explored in the following pages.

Chapter 1

Introduction



Photo by: Ditte Campbell August 2010. The counter, the discretion line and the sign. The sign reads: “Please respect the discretion line”.

I walk down a short corridor and reach an unmanned counter; on my right-hand side, I see a waiting room, which I enter. In a corner of the waiting room, there is a space for pamphlets and brochures; some are about HIV. I walk back to the counter, and in front of it, I notice a broad yellow discretion line. On the counter, there is a sign that states: “Please respect the discretion line”. The line is more than a meter from the counter, and I think to myself that discretion must be more pressing here than in other places.

(Field diary, August 24, 2010; edited)

This quote describes my first encounter with Aarhus University Hospital in Skejby and its outpatient clinic for infectious diseases. In this connection, locality and all the other material entities – such as the sign, the brochures, the counter, the corridor, etc. – become of great importance. Apart from this, it is evident that something sensitive is at stake; something that requires greater discretion compared to other places where one might find a discretion line. Both the discretion line and the locality are part of the phenomenon that I seek to investigate. The starting point is Aarhus University Hospital, Skejby, which has hosted the Youth Group since its founding in 2000.⁵ Two HIV-counsellors working at Skejby, Tinne Laursen and Lotte Rodkjær, started the Youth Group to focus on adolescents and young people between the ages of 15 and 25 who are HIV-positive. Through their work at the hospital, the two counsellors experienced that these young patients were very sad and lonely in comparison to older patients with HIV. The Youth Group offers young people in Denmark an opportunity to meet others their own age who are also HIV-positive, and thereby to help them find ways to live with this chronic disease. Initially, the group consisted of only five youths, who met with Tinne and Lotte once a month to talk about HIV. The project was meant to end after a year of these meetings, but the young patients expressed a desire to form a group that met once a year for an annual weekend trip; furthermore, they wanted to open the project to include participants from all over Denmark (Laursen & Rodkjær 2009: 4-

⁵ The Group of Young HIV Positives: <http://eng.ungegruppen-dk.dk/>. I will refer to The Group of Young HIV Positives as the Youth Group.

5). This thesis investigates how youths who are connected to the Youth Group live with this chronic disease; that is, HIV.

Empirical data

The thesis is built upon empirical data gathered at multiple sites in Denmark from August 2010 until April 2011, and I have thus engaged in a multi-sited ethnography (Marcus 1998: 79-91). I have *followed* my object of investigation to different sites and conducted fieldwork at Aarhus University Hospital in Skejby, and Rigshospitalet and Bispebjerg Hospital in Copenhagen (ibid.). I followed and observed one of the Group's founders, Tinne Laursen, for a day's work at Skejby, and I followed and observed one of my informants at Bispebjerg Hospital and Rigshospitalet – specifically, for a check-up with his physician to get blood samples, and to visit a clinic for venereal diseases. In addition, I participated in the Youth Group's annual weekend trip from October 8-10, 2010, as well as a theme day about HIV-positive adolescents and youths at the pharmaceutical company GlaxoSmithKline, and in a discussion about adolescents and youths in the Danish Health Care System with physicians from different pediatric departments in Denmark. I conducted two individual interviews and one group interview with three participants, all of whom are HIV-positive youths from the Youth Group. Part of the interviews utilized an ethnologic design game as an alternative technique for talking about a topic such as HIV, which is related to sensitive and very personal issues. I also interviewed Tinne Laursen. This empirical data forms the foundation of my thesis, and the fieldwork shaped how the thesis has been structured in combination with the choices I have made concerning its theoretical framework. Because my fieldwork was conducted over a long period of time, it allowed me to gather qualitative data, analyze it and later return 'to the field' to gather more material. This resulted in a process where I stayed open to new opportunities, but also where I alternated between collecting material, writing and analyzing.

Language

The majority of my data was gathered in Danish; I spoke Danish with people at the hospitals, during the weekend trip and in three of the four interviews with the HIV-positive youths. One of my interviews was in both Danish and English. This resulted in an extra layer of analysis in connection with first transcribing my interviews, writing my field diary, etc., and then translating the material from Danish to English. This thesis has thereby changed the collected data by presenting it in a different language than the one in which it was gathered. My choice to write in English was made to facilitate a comparison between how adolescents and youths in Denmark live with HIV, and how the disease is *done* in other countries. Thus, the thesis is "made to travel" (Mol 2002: ix-x), and this choice also becomes part of the applicability of this thesis (see page 6).

Problem definition

This thesis answers the following questions and centres on two different focal points:

1. How is HIV performed in different *versions*?
2. Do the youths emerge with new capacities after their participation in the annual weekend trip?

The first one is how HIV is performed in different *versions*. These versions come into being within different settings; e.g., at the general practitioner, in the outpatient clinic. Other versions of HIV are performed outside of treatment facilities and are related to how HIV affects the young HIV-positives' social lives and centres on *stigma* and modes of ordering. The first question thus is divided into two

separate sections. The second question takes its point of departure in the work of the Youth Group and is concerned with the Youth Group's annual weekend trip.

Theoretical inspiration

This thesis explores and analyzes how young people who are connected to the Youth Group *enact/perform* HIV. By using these words, I indicate the theoretical foundation of this thesis. I situate my analysis within a performative framework that focuses on how a single disease, such as HIV, is *done* or *enacted* in practice, and how a single disease thus becomes multiple. These theoretical concepts are part of what is called the *performative turn* within science and technology studies (STS), which is explored by, among others, the Dutch philosopher Annemarie Mol (Elgaard Jensen 2001: 67). In one research project, Mol investigates how a disease (atherosclerosis of the leg arteries) is enacted in a single Dutch hospital (Mol 2002: preface). According to Mol:

“It is possible to refrain from understanding objects as the central point of focus of different people's perspectives. It is possible to understand them instead as things manipulated in practices. If we do this – if instead of bracketing the practices in which objects are handled we foreground them – this has far-reaching effects. Reality multiplies. The body, the patient, the disease, the doctor, the technician, the technology: all of these are more than one. More than singular.”
(*ibid.*: 4-5).

This position implies that HIV may be viewed *not* as a single disease but instead as a multiple one, enacted in different versions. These different versions are connected and related to one another but are shaped in practice (*ibid.*). Mol writes that “things are manipulated in practice”, and it is *in practice* that (all) things – e.g., diseases, consultations, patients, etc. – are shaped and come into being. I thereby refrain from viewing HIV as a single disease analyzed from different perspectives, which has often been the starting point in the analysis of diseases within medical sociology and medical anthropology (*ibid.*). Thus, I do not engage in a distinction between *disease* and *illness*, where illness is the centre of investigation for the social scientist and the focus is on the patients' perspectives. If I had followed this distinction, the object (i.e., HIV) would have existed all on its own, as an unmarked object – looked at from different perspectives (Mol 2002:12). Instead, I present how HIV is enacted by youths in different places: in a hospital setting, in the youths' lives outside of the hospital, and as part of the Youth Group's annual weekend trip. Thus, HIV exists in several versions, which are shaped in their different practices. The first part of the analysis focuses on the *versions* in the hospital setting; these versions are contrasted by my focus on other version(s) of HIV that are situated outside of the hospital. Here, HIV is sometimes kept secret – as something that affects the youths' inclination to enter into relationships, and which necessitates lies if they do not disclose their status as HIV-positive. In this connection, Erving Goffman's conceptualizations of *stigma* become applicable (Goffman 2009), in combination with John Law's *modes of ordering* (Law 1994), and both concepts are utilized to explore and define how HIV appears there. Keeping HIV a secret is related to the youths' fight for recognition, and also to how HIV is perceived by others. In these versions, the youths' fear of being *not recognized* by others is one of the reasons why they keep HIV a secret (Goffman 2009: 46). The third focal point is the annual weekend trip, which is framed as a *dispositif*: a place or a set-up where the young participants might be “induced into action” and thereby emerge with new capacities (Gomart 2004). These separate questions are all related because they refer to how HIV is enacted by the youths, and how HIV exists in multiple versions.

Applicability

At the University of Copenhagen, the Project and Career Advisory service coordinates collaboration between trades/industries and students. I read through the outline of project proposals being offered and found one topic particularly interesting: the Youth Group. The project description was designed by the two founders and, among other topics, they wanted interested parties to investigate how adolescents and youths live with HIV (http://www.ungegrupper-dk.dk/50_idékatalog.htm). The project caught my attention because I already wanted to investigate a chronic disease and how people's lives are affected by it. Furthermore, I have always considered HIV and AIDS to be diseases with many different implications – including stigmatization. The collaboration has thus affected my point of departure, but it has furthermore granted me access to events, such as the theme day at GlaxoSmithKline and the Youth Group's annual weekend trip, and to informants.⁶ The knowledge accumulated in this paper is applicable in the work with HIV-positive adolescents and youths. The thesis is not only relevant for physicians, nurses or counsellors working within the field of HIV and AIDS, but also for patient organisations and other health personnel working with young patients who have chronic diseases. Health authorities could furthermore benefit from my insights for a better understanding of the lives of young patients with chronic diseases.

One of the aims of the Youth Group is to create awareness of HIV and hopefully make life easier for people living with the disease, especially for adolescents and youths; in this respect, the hope is that my research will have a positive effect. On a personal level, one of my aims is that this thesis will illustrate the continuous work involved in suffering from a chronic disease, and that it will create a better understanding of some of the ways this work affects the HIV-positive youths. I initially thought that my focus would be 'the suffering patient', but as I met and interviewed the young HIV-positives, I came to realize that this is not (always) the case. Thus, my thesis can also be used as an example of how chronic patients are not necessarily suffering, which thereby illuminates both positive and negative aspects of this disease.⁷ The research can also be utilized as documentation of the Group's work, in relation to funding to legitimize the work of the Youth Group. Furthermore, in a comparative approach, the potential of this thesis is two-fold: one can compare how the lives of patients with other chronic diseases are both different from and similar to the experiences of the HIV-positive youths; and one can compare how HIV affects youths in other countries. This second comparison is another reason why I chose to write the thesis in English.

Structure

The thesis consists of four chapters: The **first** chapter contains the introduction and briefly outlines the context within which this thesis is positioned. It also includes methodological reflections concerning the empirical data; i.e., how it was gathered, which methods I used, and a description of this material. The second and third chapters contain my analysis. Specifically, the **second** chapter centres on the theoretical foundation of the thesis and how HIV is enacted in a hospital setting; e.g., in different *versions*. It also includes a description of how the patient can be and has been conceptualised and perceived, which leads to an understanding of what is required of a young HIV-positive patient. The analysis of how HIV is enacted in its *clinical version* leads to the **third** chapter, which focuses on how HIV affects the youths' inclination to enter into relationships, how some of them keep HIV a secret, and thus how HIV is enacted in the youths' social lives. The third chapter presents these points of departure, and the analysis utilizes Erving Goffman's concept of *stigma* and John Law's *modes of ordering*. The Youth Group's annual weekend trip is also analysed by focusing on what the youths acquire within that setting, and whether they emerge with new capacities. The **fourth** and final chapter returns to a

⁶ How the collaboration has affected this thesis will be explored further in the section about method.

⁷ This will be explored in the section about the Youth Group and its annual weekend trip.

discussion from the second chapter, how to live *well* with HIV. The chapter ends with a conclusion of the points made in the thesis.

About method

The following section describes the different methodological approaches I have utilized to explore different versions of HIV in a Danish context. Here I examine the process of investigating ‘my field’ and how this collection of data affects my analytical material. It thus illuminates the techniques I have used to grasp the complexity and the steps I have taken to explore the heterogeneous elements of how HIV is enacted/performed by young people in Denmark.

My point of departure was a description of projects at the Project- & Career Advisory Service, which; “promotes cooperation between university students and private and public organisations outside the academic world” (<http://samf.ku.dk/pkv/english>). This allows both the student and the outside actor the opportunity to join forces and collaborate within a certain field and for the student to engage in concrete projects which can be utilized by the outside actor. The onset of my investigation thereby entails an element of applicability as the project itself was initiated by an actor outside of the University of Copenhagen. As I was searching for a suitable topic for my thesis I came across the project description of The Youth Group.⁸ The group is centred on creating an opportunity for adolescents and youths, between 15-25 years who are HIV-positive, to meet and interact. The founders arrange an annual weekend trip where HIV-positive adolescents and youths can meet like-minded e.g. people who are in the same situation as themselves. Adolescents and youths who are connected to HIV-treatment facilities, or otherwise become aware of the group are offered the opportunity to go away with the Youth Group. A part from the young participants and the two founders, a nurse and physician from departments for infectious diseases are invited to experience a weekend trip. These health personnel (nurse and physician) get to interact with the adolescents and youths, and spend time with the two founders. As such the weekend trip is both a place where the participants can relax, take their medication openly and not worry about their HIV-positive status, as well as a place where the Youth Group is promoted to outside actors - thus; spreading the knowledge of the Youth Group is also part of the weekend trip. The aim is that the participating health personnel acquire knowledge about this specific group of patients and the work of the Youth Group.

To gather and create knowledge and attention about this group of patients the two founders created study cases, which the Project- & Career Advisory Service posted on the web page. The two founders sought to:

“Increase the knowledge about the social consequences of being infected with HIV and the value of a goal oriented effort towards supporting HIV-positive adolescents. The aim is to create greater attention about the subject matter, and inspire the Danish scientific environment.”

(http://www.ungegrupper-dk.dk/50_idékatalog.htm, my translation).

As indicated the Youth Group’s aim is to inspire others to produce knowledge about adolescents and youths who are HIV-positive.⁹ The HIV-positive adolescents and youths are part of the statistical

⁸ For background information about the Youth Group see introduction.

⁹ Since the discovery of the disease people living with HIV and AIDS have taken part in activism. The Youth Group also becomes part of this political activism by initiating research about the topic and distributing this new knowledge.

knowledge about HIV¹⁰ but they are furthermore active in providing information about the subject matter by volunteering for interviews by interested parties such as me.

About the informants

I have interviewed five HIV-positive youths between the ages of 25-28; consisting of four males and one female whom all had been infected with HIV when they were between 18-22 years old. All of them have been transmitted with the disease via sexual contact. Two of them are homosexuals, two are heterosexual and one is bi-sexual.¹¹ Besides this two of them are students and the other three have full time employment. At the time when I did my field work three out of the five informants were on medication. All five informants are connected to the Youth Group and take part in different activities e.g. the weekend trip, conferences, interviews and as mentors for younger participants in the Group. Initially I did not seek only to incorporate informants who were members of the Group but as my field work progressed I decided to grant the annual weekend trip and as such the Youth Group a separate part of the analysis. It thus, made sense not to incorporate informants who had not participated in the Youth Group. This selection underlines the contingent nature of social scientific research, because as my field work progressed a specific selection of my research topic appeared useful and telling in regard to the lives of these youths (Aull 2008: 29- 30). Despite the narrow outlook I do not claim that HIV-positive youths, who have never participated in any activities related to the Youth Group, enact HIV differently but I merely specify the context of this particular investigation. Through out the thesis I have chosen to use the same names in the quotes, which enables readers to follow a particular informant and his/her performance of HIV. All the names of the informants have been changed to grant them anonymity.¹² I have chosen to use the real names of counsellors and coaches because they appear in relation to their profession.

Empirical data

As I have already in the introduction mentioned the different activities that my empirical data consist of I will only briefly mentioned them here: a day at Aarhus University Hospital with Tinne Laursen, a theme day at GlaxoSmithKline, weekend trip in October 2010 with amongst others a master student: Nikolaj Darre. Besides this I followed one informant: to get blood samples taken, to a check-up and consultation and at a venereal clinic. I also participated in a discussion about adolescents and youths initiated by the Association of Paediatricians. I have conducted four semi-structured qualitative interviews which consisted of: three individual interviews, one of them included a design game and one group interview also consisted of both an interview and an ethnologic design game about HIV. In June 2011 I participated in and presented part of my project at Aarhus University Hospital to interested parties as part of a presentation of what kind of work the Youth Group is involved in.

Access

As mentioned I started my investigation connected to the Youth Group, where I was mainly in contact with one of the HIV-counsellors: Tinne Laursen. As such she functioned as my primary gatekeeper as

¹⁰ When a citizen is found HIV-positive this information is sent to Serumsinstituttet and kept for preventive and statistical purposes.

¹¹ I have not focused particularly on this topic in this thesis except for an explanation to a quote and in regard to the definition of risk groups.

¹² I have interviewed one of the HIV-counsellors from the Youth Group: Tinne Laursen and I have not changed her name or the names of the coaches who only appear in the section about the Youth Group.

she invited me to participate in relevant events.¹³ She furthermore acted as intermediary in establishing contact with the youths who wanted to participate in this investigation. Tinne Laursen provided their contact information and the subsequent agreements were made between the informants and I. As mentioned I conducted one group interview which was a collaboration between Nikolaj Darre and me. This interview was initiated during the last day of the weekend trip where the three informants agreed to participate in a group interview and therefore approached us. Tinne Laursen and the activities she was invited to as a part of her job thus functioned as empirical data in connection with this thesis because she was my primary gatekeeper (Aull 2008: 54).

Re-negotiation

After having established the initial contact with one of the informants I asked whether I could follow him to a check-up at Rigshospitalet, which he consented to. As such the HIV-counsellor was my primary gatekeeper who provided access to my field of investigation and subsequently I was then able to get further access to the lives of the informants by re-negotiating the terms.

The location of the field

In the introduction I have mentioned that I engaged in a multi-sited ethnography, I will explore the matter in detail here.

Historically, anthropological and ethnographical studies focused on remote and isolated communities where the location became equivalent to the object of investigation; a *single sited* ethnography, which took place in a bounded geographical setting (Marcus 1998: 90). Instead of engaging in a single sited ethnography I have ventured into a *multi-sited* ethnography. According to Marcus:

“Multi-sited ethnographies define their objects of study through several different modes or techniques. These techniques might be understood as practices of construction through(pre-planned or opportunistic) movement and of tracing within the different settings of a complex cultural phenomena given an initial, baseline conceptual identity that turns out to be contingent and malleable as one traces it.”

(Marcus1998:90)

The starting point of George Marcus’ argument is an investigation in two modes of ethnographic research: a single sited and a multi-sited both in regards to the field and investigation. The single sited ethnography is a historic mode where the context of the locally situated field work was established through “working in archives and adapting the work of macro theorists” (Marcus 1998: 79). The change towards a multi-sited ethnography was mainly initiated through interdisciplinary areas such science and technology, feminist and media studies. These changes were initiated because the interdisciplinary fields did not have a bounded object of study. Furthermore the focus upon cultural process which came in the wake of ‘postmodernism’ also provided ideas and concepts towards this move. Besides this “the transformed location of cultural production” (ibid.:80) e.g. “the circulation of cultural meanings, objects and diffuse time-space” impelled this move as well (ibid.: 79). The changes are mainly applicable within methodology according to Marcus. The object is understood as situated in many different places and is thereby also mobile. To engage in a multi-sited ethnography one has to follow different modes or techniques; the object thereby also reveals its self as contingent. In this

¹³ Tinne invited me to participate in the theme day at GlaxoSmithKline, made me aware of the discussion by the Paediatric Association and invited me and Nikolaj Darre to participate in the weekend trip.

respect I follow 'the thing' i.e. HIV to the settings which it is enacted and performed. Obviously I stay loyal to my theoretical inspiration and consider objects to be human and non-human entities (Marcus 1998:92).

Initially following my object of investigation to its different settings might seem like an easy task but because most of my informants do not live openly with being HIV-positive. I did not find it relevant to follow my informants to their private homes, at work or outside of their daily activities (a part from treatment etc.) but I think it could have been difficult; because how do you explain a researcher who follows you around if you meet somebody who does not know the informants HIV-status? In connection with the interviews one of them took place in the privacy of my home, one was at a NGO connected to HIV and the third was at Aarhus University Hospital Skejby. Thus the object affected where these interviews could take place. The last interview was also at Skejby – which is the work place of Tinne Laursen. To analyse how HIV is enacted, it has been necessary to use the patients as ethnographers because I have only been able to follow informants in a limited way. Through design games and interviews, my informants became ethnographers, describing the events that have occurred in their lives, and how they have been affected by the disease (Mol 2002: 15).

Choosing a topic

The collaboration with the Youth Group affected not only the collection of my empirical data but also my research topic. Albeit the project was initiated by the Youth Group and its two founders, I have also kept a reflexive approach towards how this has affected my research. Charlotte Aull Davies states that when researchers choose their topic it is an interstice of the researchers' personal biography, the intellectual climate and the socio-economic situation (Aull 2008: 30-31). In regards to my choice of investigation it is shaped by growing up when HIV and AIDS was in focus via both the Danish prevention schemes and sexual education in public schools. Besides this the moral implications in connection to HIV and AIDS underlines how this disease differs significantly from other diseases which is also part of my motivation. Besides this the effort and continuous work of living with a chronic disease is an area of great interest of mine. In relation to the scientific climate there is at the department of Ethnology a great interest in the performative turn which has inspired me to follow this theoretical approach. Fully comprehending all the reasons why one engages in specific topic of research seems unrealistic.

Insider or outsider?

In the article *The Risk of going observationalist. Negotiating the Hidden Dilemmas of Being an Insider Participant Observer* (Labaree 2002). Robert Labaree focuses upon and discusses participant observation and the conceptualization of *insiderness* and *outsiderness*. In the following I draw on his discussions and conceptualizations to explore the topics of being an insider or outsider.

When an anthropologist/ ethnologist/cultural analyst enters their field of investigation, access and their positioning as either insider or outsider can appear as a methodological dichotomy. As such the position of being an insider is often believed to offer distinctive advantages concerning both access and understanding of the culture of investigation (Labaree 2002: 97). "Insiderness is considered revealing in an epistemological manner that is considered inaccessible to an outsider" (ibid.: 99). Being native and an insider is thus perceived as giving access to both hidden meanings and result in a "necessary" great level of trust (ibid.) In that conceptualization insiderness and outsiderness becomes polarized and assumptions about these positions are loaded with presumptions. Instead according to Labaree, one should rather conceptualize the relation between subject and object as one of multiple insiders and outsiders (ibid.: 101), which allows the researcher to go into depth with his/hers position and avoid presumptions about the advantages in this respect (ibid.). In connection with my field work I am a

native insider because most of my informants have been brought up in Denmark. We have similar experience in connection with educational background and how HIV and AIDS were and are portrayed in the public media, prevention schemes etc. One of my informants is from a country in Africa and in this respect I am an outsider, with no experiences with his geographical region. My informants were between 25-28 years of age and I am 33 so in that respect I consider myself in a position as an insider. I felt that I could relate to their problems and joys in connection with relationships, falling in love or being single. During the weekend trip when I was doing participant observation I found myself relating to problems the youths discussed with their coaches, Hawk and his wife (see section about HIV- a gift?). In regards to investigating HIV and AIDS I am an outsider as I am not HIV-positive. I thus consider myself to be in a multiple insider and outsider situation. As part of my interviews my informants disclosed: that you cannot fully understand what it feels like to be HIV-positive if you are not infected with the virus. I initially concur that I cannot fully understand what it feels like to be HIV-positive but other aspects of my life can serve as experiences of rejection, not being recognized or other of the topics which this thesis touches upon- which can give me an idea about how it feels. Despite the fact that the youths saw me as an outsider I hold on to being in multiple outsider and insider positions.

To grasp the complexity of the daily lives of the HIV patients I wanted to explore other techniques than participant observation and semi-structured interviews. To engage in and utilize other ways to gather data from my informants I found inspiration in methods developed for user-driven innovation which has been used in ethnologic research.

An ethnologic design game

Design Games have been used by designers as a tool to investigate possible futures and everyday lives of game participants in user-driven innovation (Brandt et al. 2008:1-3). The game can be designed to fit the purpose of the initiator and thereby allows the facilitator to investigate a topic or setting of their choice. The game pieces are designed to fit the subject in question, which makes it applicable in settings other than user-driven innovation. In an ethnologic context design games have recently been explored and developed as a method for gathering information about everyday grocery shopping (Breddam & Jespersen 2010: 16). In this connection the design game allowed the ethnologist to acquire insights in how grocery shopping was done in different households. The game consisted of different game pieces which allowed the informants to recall how their shopping occurred. Each game piece thus made the informant remember if they did their shopping on their own, made a shopping list or whether they only shopped once a week etc. The game made the informant recall and explain the different elements involved in their shopping, and the ethnologist gained insights in what choices the informants made and why. Additionally the game allowed more than one participant which lead to discussions about how the household shopping was done (ibid.). In user-driven innovation and in an ethnologic design game, design games have, amongst other things, been used to explore the complexity of everyday life of either participants or informants. Inspired by the two aforementioned types of games I wanted to design a game as an explorative approach to unfolding some of the aspects of living with HIV.

A design game takes place in a nexus between a 'normal' board game with an element of fun and a topic of investigation. When playing the game the facilitator; in this case me, explains the rules of the game and the game commences. This approach allows the informants to choose which category they would like to talk about and thereby installing a choice. The informants are thereby also part of 'setting the stage' and deciding what topics should be addressed in which order. ¹⁴

¹⁴In this case the fun element can seem provocative because the topic of a more serious matter but in my experience being able to choose and thereby set the stage meant that the discussion flowed more freely. One comment from an informant sparked off a comment by one of the other participants. At the same time both Nikolaj Darre and I could ask follow up questions.

The design game I developed consisted of seven categories/pieces which were: HIV, CD4 numbers, The Youth Group, Consultations, Medication, Everyday life and Secrets. The seven categories were visible from the outset of the game and further pieces were turned bottom up, not to reveal the next piece beforehand. As such the choice the informants had was which topic they wanted to talk about and when.

As mentioned HIV is a disease where issues of sexuality, moral and relationships are part of the areas which are effected, this implies that privacy, sensitivity and ethics become relevant, because how do you investigate very private issues with respect for the informants and which questions are too private? This was one of the reasons behind choosing to explore alternative methods but also to alleviate talking about HIV. Besides this the game was initiated to create a space where it might be easier to talk about personal topics such as sexuality but also enable a more comfortable situation in which to discuss previous experiences such as: rejection by partner, compliance in relation to medication, safe sex etc., which might be difficult.

I played the game twice once as part of an interview with one informant and the first time I played it was with three informants and two facilitators e.g. both I and the other master student Nikolaj Darre facilitated the game. The game did result in interesting and useful information about living with HIV and as the three informants knew each other very well it generated insights where they asked each other questions or commented on how they felt about a specific topic and why. The design game has some of the qualities in regards to generating knowledge (i.e. that the techniques requires discussion which illustrates diversity and differences between the informants) and in this case how they are affected by HIV. The following quote illustrates how the informants during the design game commented on what each other said but it also underlines their connection e.g. being friends. Morten, Søren and Anna are talking about the Youth Group and the changes in how they feel about HIV now and how they felt in the beginning when they were first diagnosed.

Anna: That is something I would have never thought when I was told [that I was HIV-positive]. Then, I just thought I was going to die. I thought everything was negative, and that I would have to take what I could get. Even if it was some disgusting guy who wanted me, then I would just have to be happy.
(informants laugh)

Anna: That was my thought at the time, but because of the process I have been through, and primarily because of the Youth Group, it's meant that I am – it sounds sick but...

Morten [finishing Anna's sentence]: You are pleased about being HIV-positive?

Anna: I just think that I can mention many more positive things [about] being infected than negative.

Morten: I think that is important to get across. "You feel bad about being HIV-positive or what?" "No, I feel fantastic".

Anna: It sounds really strange because at the same time I wouldn't wish [this] on anybody else. (...) But the way my life is now – anyway, it has given me more than it has taken from me, I think.

Søren: (...) For me, it has been the best decision I ever made – it was to agree to go on a weekend trip.

Morten [adding to Søren's answer]: – was to not use a condom.
(informants laugh)

The sarcastic comments, the laughter and the expression of how they feel illustrates how well they know each other and also how the insights gained from the ethnologic design game came about.

Interviews

In addition to the ethnologic design game I also conducted interviews; these were semi-structured which enabled me to stay open to both adding additional questions, following an unexpected line of questioning or changing the structure of questions if I needed to. In this connection I see the interviews as “an examination of the production of meaning through which the social world” is constructed (Mik-Meyer& Järvinen 2005: 16, my translation). I thus do not view the qualitative interview as a technique to uncover the lives of the informants if these are defined as stable and just waiting to be uncovered by me, the researcher(ibid.). As mentioned utilising interviews as a technique to gather material resulted in a vast amount of data which I subsequently have transcribed and analysed. As mentioned in the introduction I have gather, transcribed and analysed the material along the way and at the same time remained open towards new possibilities.

During one of the interviews I worked with Nikolaj Darre and as such both of us facilitated an interview and the ethnologic design game. We thus all co-constructed the interviews.

This section has explored the different techniques I have used to gather my empirical data and thus concludes my section on method.

Chapter 2

Theoretical foundation

This section centres on the theoretical foundation of my research, which affects both the methodological and analytical aspects. I position this thesis in opposition to *perspectivalism* and to understanding a disease as a single entity. The emphasis is on *practices* and how objects are *enacted/performed*, and this implies a specific view on how reality is constituted and which elements should be incorporated in the analysis. Furthermore, it establishes a specific view on *illness* and *disease*; a separation well-established within the rich disciplines of medical anthropology and medical sociology (Mol 2002: viii). In the following section, I first make an account of the context of *the performative turn*, then I describe and apply my choice of theory, thus illustrating how HIV is diagnosed.

The performative turn

Before venturing into an analysis of the diagnosis of HIV, I will briefly describe the theoretical and analytical context of the *performative turn*. The performative turn is derived from actor-network theory (ANT), which is founded on an ontological assumption that an entity – e.g., a disease, a man, a gust of wind, a technology – is constituted by its relation to other entities (Elgaard 2003: 6). As such, ANT and the performative turn are a *semiology of objects* because all entities come into being in relation to other entities in the network. The networks are heterogeneous, and the objects are continually “constituted and re-constituted” (Elgaard 2001: 78); objects do not have an essence nor “exist in and of themselves” (ibid.: 67). The heterogeneity explains the type of relations that are part of the network; it can be both human and non-human entities – the network is heterogeneous (Elgaard 2003: 22). An *actor* (actor-network theory) is “anything that is ascribed agency or admitted to be the source of agency in a situation. So any kind of ‘entity’ (machines, materials, persons, institutions, animals, particles, etc.) can figure as an actant in ANT’s analyses” (Elgaard 2001: 58). ANT has, among others things, been criticised for centeredness and being too functional. This criticism claims that the (ANT) analysis establishes how a centre succeeds in rectifying the surrounding world (ibid. 2003: 24) – an answer to this criticism is found in the work of Annemarie Mol (2002) and John Law (1994), which shows how the world (instead) consists of several partially connected performances of any phenomenon; e.g., multiple objects (Jespersen 2007: 44). There are several networks and not one privileged place or centre from which actor-networks can be ‘viewed’ (Elgaard 2003: 25).

Perspectivalism

Within medical sociology and medical anthropology, there has been a division between at least two opposing perspectives: namely, disease and illness (Mol 2002: preface viii). Whereas *disease* was the focus of physicians who treated medical physicalities, the social scientists focused on what the doctors did not handle, and they claimed that there was something “more” to disease (ibid.). This “more” was “a social and an interpretive reality” e.g. *illness* (ibid.: viii-ix), and the medical perspective was later included and investigated in these studies (ibid.). As such, *perspectivalism*:

“...broke away from a monopolistic version of the truth. But it didn’t multiply *reality*. It multiplied the eyes of the beholders. It turned each pair of eyes looking from its own perspective

into an alternative to other eyes. And this in turn brought *pluralism* in its wake. For there they are: mutually exclusive perspectives, discrete, existing side by side in a transparent space. While in the centre the object of the many gazes and glances remains singular, intangible, untouched.”
(Mol 1999: 76)

If this separation is followed, then according to Mol, it becomes possible to view a single disease from an endless array of different perspectives, which again leaves the object untouched; it leaves the object ‘out there’, existing outside of practices, and as such ‘singular, intangible, untouched’. Instead, she believes that we should focus on practices: on how a single disease is ‘done’ by engaging in a praxiography, which reveals that the object in focus is multiple (Jespersen 2007: 44). In her book *The Body Multiple*, Mol describes how a single disease – atherosclerosis of the leg arteries – is *done* in a single Dutch hospital. This somewhat strange formulation indicates Mol’s aim: to articulate a radical new way to analyse diseases (ibid.). When one focuses on practices, it has profound implications: Instead of an epistemological understanding of how reality should be known or what constitutes true knowledge, one should rather tune into an ontology of practices. It is in practice that objects, such as a disease, come into being (Mol 2002: 5). To phrase it another way:

“Reality does not precede the mundane practices in which we interact with it, but it is rather shaped within these practices.”
(Mol 1999: 75)

By focusing on practices, a disease becomes “more than singular but less than many” (ibid.). Thus, HIV becomes more than a single disease – it becomes multiple. In a brochure about HIV, it is described as a disease caused by a virus that slowly deteriorates a human’s immune system by attacking the white blood cells, which are also known as CD4 cells. If left untreated, this can develop into AIDS (Nielsen 1994: 17). In this medical description, the disease is a single thing – it is a single object described from a medical perspective, which ‘brackets the practices in which the object is handled’. In the following section, I follow HIV – not as single phenomenon, but as a multiple one that exists in different versions. By attending to multiplicity, it is also implied that the different versions of HIV are somehow connected, intertwined and coordinated; they exist alongside each other (Mol 2002: preface - 6). The aim and purpose of my project both follows and differs from Mol’s. Similar to Mol, I follow a single multiple disease (i.e., HIV) and investigate how it is enacted in different versions. In Mol’s analysis, the various performances of a disease unfold themselves within the different departments of the hospital, which are referred to as ‘sites’ or ‘settings’ (Mol 2002: 159). Initially, I concur with Mol, but I follow the enactment of HIV to different locations; I describe how this is done, but refrain from focusing exclusively on a single setting. Instead, my analysis discusses how young people who are HIV-positive perform the disease; as such, I do not focus exclusively on how medicine enacts an object, but follow the HIV-positive youths to a check-up and focus on how this disease affects their social lives.

In the first part of my analysis, I investigate HIV in the hospital setting and thus follow Mol. But in the second part, which focuses on stigma, I follow the work of John Law and utilize his *modes of ordering* (Law 1994) with regard to the social lives of the youths. In the third part of the analysis, I focus on how the youths enact HIV within the setting of the annual weekend trip.

Diagnosing HIV

The first case describes how Søren, now 28 years old, was diagnosed with HIV just before he turned 22. He has been part of the Youth Group for six years.

Nikolaj: What made you go [for an HIV test]?

Søren: I got really ill. At first, I just thought it was the flu or something like that. I went to see my own physician, and he couldn't figure out what was wrong with me. Then they took a lot of blood samples, which were sent to Skejby, and a week later I got a really boring phone call [asking] if I could come and see the physician because there was something we had to talk about. And then Tinne was sitting there, and I was told the works.

Ditte: Do you remember how you felt?

Søren: (...) I went completely blank, and I got really upset, of course, and surprised. I have always taken really good care of myself, so I felt like – how on earth could that have happened? I started going back – who could it have been? Then a couple of months went by, and I went on my first Youth Group trip, and then everything started falling into place, I would say.

Nikolaj: What did you do in those couple of months – did you walk around in a [daze], or did you go to work or school?

Søren: (...) I think on the outside I functioned completely as usual, but of course I had been carrying the burden on my own. It took me two months before I told anybody. (...) I had to explain why I had to go to Ebeltoft for a weekend [for the annual weekend trip with the Youth Group]. If I am completely honest – I can't even remember. It's kind of a blur.

(Nikolaj/interviewer, Ditte/interviewer and Søren)

This demonstrates how HIV was diagnosed in Søren's case. He initially went to see his general practitioner (GP) because he felt ill, but his GP could not determine the cause; therefore, blood samples were taken from Søren and sent away for testing.¹⁵ The tests showed that Søren's blood contained the HIV virus, and a consultation between Søren, his GP and the HIV-counsellor was arranged.¹⁶ It was not until *this* meeting that HIV was performed in practice – it required not only entities such as the patient, the HIV-counsellor and the GP, but also other heterogeneous elements such as the clinic, the furniture and the test results. Furthermore, it partially describes how a consultation with a GP is ordered in practice (Jespersen 2007: 13): the patient/citizen with a problem, the physician trying to recognize symptoms (and in the end succeeding in) and making a diagnosis.¹⁷ As an effect of the consultation, the patient (i.e., Søren) is diagnosed with HIV (ibid.: 13). The HIV diagnosis also created a lot of emotions for Søren ('getting very upset...and surprised') because he thought that he had 'taken really good care' of himself. In addition, Søren describes that afterward he 'functioned completely as usual but carried the burden on [his] own', which reveals how being diagnosed with HIV is not necessarily something one shares with others.¹⁸ Søren's diagnosis is one version of how HIV can be enacted; one that is shaped by specific elements, which will be explored in comparison with another version.

¹⁵ Just before Søren was diagnosed with HIV, he had moved back to his parents' place because his father had been diagnosed with cancer. While he was there, Søren got ill and consulted his GP.

¹⁶ The closest HIV clinic was at Aarhus University Hospital, Skejby; therefore, Søren was assigned to its outpatient clinic. The hospital has two HIV-counsellors, and when a GP has to deliver an HIV diagnosis, they are called to be present. In Søren's case, one of the counsellors helped to deliver the message.

¹⁷ I write partially because when you use informants as ethnographers they do not register everything you wish they would, they do not necessarily recall it or it does not seem important to them. I will reflect more on this matter in the section: About method.

¹⁸ The comments that Søren thought that he had 'taken really good care' of himself and that he carried the 'burden on his own' will be further explored.

Another version

Another informant, Anna, explains how she got infected and diagnosed with HIV, which occurred in an altogether different way than Søren:

Anna: I was told in 2006 that I was infected. [It happened] a year prior to that in Sydney, Australia, where I had met a guy I was seeing for a little while. Like Søren, I don't really know why. I always thought I've taken good care [of myself]. I don't think that I've been around that much. (Laughs aloud) But then I got really ill down there.

Nikolaj: In Australia?

Anna: In Australia, I had the flu – just around New Year's. I actually couldn't celebrate New Year's. (...) I had flu symptoms and just threw up. That must have been the phase of acute HIV, or whatever they call it. I went to see a physician, and he just thought that it was a stomach infection. He actually asked me if I could be pregnant, and I just thought: "No, I'm on the [birth-control] pill." Nothing else really came to mind that I thought it could be. After I had been ill for a week, then I felt fine again, [and I thought], "It's just the water down here". Then I came home [to Denmark], and six months later, I went for a tapping of blood – I'm a blood donor. After that, I got a few calls on my cell phone from a non-registered number, but I never really take those. Then I received a letter from the hospital, which said that I had to contact them. And I just thought, "They must need more of my blood, because it's that good". (Informants laugh) Very naive. The physician on the phone said that they had found something in my blood, and they thought it was HIV.

Søren: On the phone?

Anna: Yes, he actually told me over the phone. I have also since then thought that it was a bit strange.

Søren (sarcastically): Just a bit.

Anna: I remember that I was just on my way out to visit my sister: "No, that can't be true what you're saying", and [he said], "You should probably come to the hospital to get it confirmed". I just thought, "No, this can't be true – I would rather have leukaemia, it sounds better." I just thought, "HIV – that is just not part of my world, that is just not something that could happen to me". I don't think I really got it at all. Later that day, I had a job interview, so I felt like, "Well, I am not going to the hospital – it will just have to wait a little while". I tried to keep my appearance [normal] when I went to see my sister, but she could tell that something was wrong right away, and I completely fell apart. Then I realized that it was probably a good idea to go to the hospital. We went to the hospital in Helsingør, and there was a really nice physician and a nurse who said, "Everything is going to be OK". I don't remember very much – they took a lot of new tests. The day after, I came back with my parents and they told us a lot more, I think – that I could live a normal life, have children and other things. But I think I still felt a bit like, "They are not my tests, those ones." (...) I chose not to tell anybody – just my siblings and my sister's best friend, who is like a sister. (...) I didn't really have the courage to tell anyone else, even though I thought that people would be nice about it. I don't think I had accepted it completely. The first six months, I just lived. (...) I can't really remember that much about it. I was fine, as you say.

(Nikolaj/interviewer, Ditte/interviewer, Anna and Søren)

In Anna's case, being diagnosed with HIV happened over the phone, and not because she had been ill beforehand or suspected that she had been exposed to HIV – instead, it was because she donated blood.¹⁹ The HIV diagnosis required reaching Anna by mail since she would not answer the unregistered phone calls, which then led to enacting HIV in a phone call that she made to the hospital. The events that led to both Anna's and Søren's diagnoses are telling. They illustrate how it requires a

¹⁹ After HIV was first identified, several patients who were haemophiliacs became infected via blood transfusions; because of this, all donated blood is now screened for HIV, which is what happened in Anna's case.

wide range of socio-material elements – a phone, a letter, a physician, blood donation, blood samples, tests and patients – to diagnose HIV, but also that some of these components are flexible (Mol 2002: 24). The flexibility is evident when the two diagnoses are compared. Søren contacted his GP because he was feeling ill, and this led to the diagnosis in the consultation room with Søren, his GP and an HIV-counsellor present, in addition to the other heterogeneous elements that were included; this is one version of an HIV diagnosis. Anna's description includes a wider range of heterogeneous material elements; specifically, she mentions the phone and the letter. In Anna's case, her mobile phone becomes of great importance, but so does the phone at the physician's end – not to mention the registration of information about blood donors and the screening of blood; this is a second version of an HIV diagnosis. Before a diagnosis, the blood has to be taken, sent to a laboratory and tested, then the results have to be sent to the physician and verbally expressed to the patient. This suggests a third version – the one performed in a laboratory e.g. the *laboratory version*. The laboratory results come before a diagnosis is possible. In this way, the diagnosis depends on these results; the results from the laboratory are privileged over the *consultation version* and the *screening version*. The different versions enacted in practice illustrate how HIV is a multiple disease, and how it is shaped within these practices. Furthermore, it becomes evident that these different versions exist alongside and are related to each other.

Detection of HIV

Søren's and Anna's cases illustrate how detecting and diagnosing HIV in Denmark are mainly organized in a *clinical manner*, and also what such an organization entails (Mol 1999: 79). When the detection of diseases is organized in a clinical manner, it requires a health care system that is equipped with professionals – those agents who, in cooperation with a patient and other heterogeneous elements, can enact a consultation that may lead to a performance of a disease (Mol 1999: 77-79; 2002: 23).²⁰ During a consultation, a physician asks questions about the patient's symptoms; if HIV is suspected, a blood sample is taken and sent away to a laboratory to be tested; i.e., another version of HIV. Even though the detection of HIV is primarily organized in a clinical manner, Anna's case illustrates how screening is another version of how the disease is enacted (Mol 1999: 79).

Feeling at risk

In both Anna's and Søren's cases, neither of them saw themselves as being at risk to acquire HIV. The questions that Anna was asked in Australia (e.g., whether she was pregnant) illustrate this point, and so does the fact that Søren did not receive an HIV test to begin with.²¹ Both Søren and Anna were surprised to be diagnosed with HIV because they did not view themselves as at risk for contracting it. As Anna says: 'I don't think I've been around that much', which illustrates that she does not think she has had very many different sexual partners, and furthermore that she has practiced safe sex.²² The prevention schemes and the organization of the health care system require a Danish citizen to contact their GP or go to a clinic for an anonymous HIV test if they suspect that they have been exposed to HIV. As illustrated in practice, people might not believe that they are at risk or have had unsafe sex;

²⁰ In Anna's case, her blood was screened and found to be HIV-positive. Screening is thus also performed as part of the diagnosis of HIV.

²¹ One of the other informants, Jonas, made an appointment with his GP because he suspected that he had been infected with HIV after practicing unsafe sex. In comparison with Søren and Anna, Jonas's consultation and diagnosis were more 'straightforward' because he had an idea about what he might be suffering from.

²² In the 1980s when HIV was first identified, a person's sexual behaviour was quickly defined as a focal point in connection to how HIV was spread. There was often an implication that people who had numerous sexual partners became infected (see prologue). In a Danish context, condoms and the practice of 'safe sex' have been part of the prevention schemes' slogans for decades; thus, for people today who are infected with HIV by sexual transmission, it may appear that it is the infected individual's own responsibility/fault.

thus, they do not consult a physician or get tested. As indicated, the different versions of a diagnosis contain other elements as well: the understanding of defined risk groups, at risk behaviour, and a lot of feelings connected to these elements.

Emotional feelings are handled²³ in a diagnosis, but they are also something that the patient has to handle on his/her own; e.g., outside of the hospital/clinic or outside of the consultation with the GP (Jespersen 2007: 109-112). In this respect, the way that feelings are handled is hinted at in Anna's case: she mentions how the physician and nurse at Helsingør Hospital told her that "everything is going to be OK"; and when she returned with her parents, they told her that "she could have a normal life and have children." These comments make sense because the youth's knowledge of HIV is not up to date. When they are diagnosed some of them think that they are going to die or that they cannot have children. In Anna's case these fears, anxieties e.g. feelings were addressed during the consultation. Feelings can thus become part of the treatment in relation to a HIV diagnosis. Feelings can be conceived of as having different kind of legitimacy, some are part of what a physician can handle but other feelings might have to be pushed aside for either some other time or something the patient has to handle outside of treatment (ibid.: 105). As the quotes from both Søren and Anna demonstrate, being diagnosed with HIV includes a lot of feelings that are addressed and handled in the consultations, but they also show that when the young patients have left the hospital, they sometimes keep their disease a secret or refrain from telling anyone other than their closest family and friends e.g. how they feel might not be addressed or talked about.

From this description and analysis, it should be apparent how HIV exists in several versions, depending on how they are enacted, and that these versions are distributed to different sites. In this connection, I have illustrated how a diagnosis of HIV is performed through two cases: in Søren's case, he was at the clinic with the GP and an HIV-counsellor; in Anna's case, she was diagnosed with HIV over the phone. This illustrates how a diagnosis can be enacted, but also that the detection of HIV is mainly organized in a clinical manner. The two cases underscore that another version exists – the one that takes place in the laboratory. The version of HIV that is enacted in the laboratory is included in the diagnosis of the disease – it is privileged over the diagnosis.

In the following section, I analyse how HIV is performed in a *clinical version* and how certain elements (e.g., CD4 count, viral load, medication) become part of the young patients' lives. In order to understand what is required of the youths as patients with a chronic disease, I first sketch out different definitions of the patient. Next, I define what this means in relation to the young HIV-positives, which is then followed by the analysis of the clinical version.

The patient – past and present

In the last few decades, the pathological picture in Denmark has changed due to a rise in the average life expectancy, which has resulted in an increase of patients with chronic health conditions. This has transformed the requirements of the Danish health system, along with changes in how patients should be treated and cared for. As such, there has been a shift in how the role of the patient is conceptualised and understood, especially in relation to chronic diseases (Olesen 2010: 307).

Generally speaking, the patient is in a position outside of the normal, due to either a physical or mental dysfunction, and is undergoing some kind of treatment. One image of the patient is that s/he is suffering while lying in a sick bed, awaiting the nurse or physician for either care or treatment. The patient is thereby a dependent individual who silently tolerates his/her suffering, awaiting and accepting any intervention by the health professionals. A medical intervention should, hopefully, enable the

²³ Feelings are handled as part of a consultation and, like all entities, are an outcome of the heterogeneous processes. Thus, they are handled, which means that they can, amongst other, become absent or present in the consultation. I use the word handled as a translation of the Danish word 'håndtering' which Astrid Jespersen utilizes instead of Annemarie Mol's enactment (Jespersen 2007: 47).

individual to shift back to his/her normal and autonomous position (Olesen 2010: 309). With regard to HIV and AIDS patients, however, a shift back to *normal* (i.e., no longer being sick) is not possible, which implies that treatment and care in this connection is continuous and necessary for the rest of the patient's life.²⁴

The conceptualisation of the patient can be positioned between two poles: At one end of the spectrum, the patient is an independent and autonomous patient subject; at the other end, the patient is a dependent and passive subject, where the latter term refers to a more static understanding of the patient and an asymmetrical relationship between patient, caretaker and physician (ibid.: 309). HIV patients are independent, but also dependent on their treatment and move between the two poles. In relation to HIV, the image of a dependent, suffering patient serves as a warning of what *could* happen if they do not follow their treatment; i.e., if they are diagnosed with AIDS. As a chronic HIV-patient, they have to adhere to their treatment; thus, the recent concept of the *active patient* may be seen as more appropriate: activity, self-care and empowerment are concepts often used in this respect (ibid.), which highlights the changes in the pathological picture, but also underscores the role of the (HIV-positive) chronic patient. In a recent publication, the Danish Ministry of Health researched how chronic patients can be better equipped to deliver self-care by being active patients, and thereby assuming some of the responsibility for their own care instead of relying on frequent visits to hospitals and/or their medical practitioners. The goal is for this to be more cost-effective and to improve the quality of life for the patients involved (Sundhedsstyrelsen 2009). For the chronic HIV-positive patient, a lot of self-care is necessary, and subsequently a lot of time and effort is required. If an HIV-positive patient is on medication, they have to take their medication and make time in their schedules for regular consultations. Also, as mentioned in the description of how HIV is diagnosed, feelings are handled as part of the treatment in the consultation. However, feelings are also something that the HIV-positive youths have to handle outside of this setting, which indicates yet another aspect of being ill. The chronic HIV-patient should therefore be seen as an active patient- responsible for their self-care. What this self-care implies will implicitly be part of the following section.

Clinical version

We meet at Rigshospitalet in the afternoon to get Chris's blood samples taken before he has to go for a check-up. I find Chris outside the waiting room, where he has already taken a number to wait his turn. The number pops up on a large screen and we walk over to a counter. He scans his identity card and the nurse at the counter hands him some sheets of stickers. (...) We wait a little while, and I ask him if he gets nervous beforehand – he says he doesn't, not until he has to go for the actual check-up, which is scheduled a week later. (...) We walk down a corridor and enter a small booth. The booths are aligned in rows with curtains as a screen between the corridor and the booth. A nurse is sitting on a chair, and Chris hands her the sheets of stickers. (...) Chris is then also placed on a chair while the nurse takes blood samples from him. The nurse attaches the stickers to the test tubes that contain the blood samples and places them on a small machine that gently moves the samples back and forth. She explains that the stickers are for the different kinds of tests he needs. I ask her about the different samples, but she says that, out of consideration for Chris, she will not answer my questions about the different kinds of tests she takes – it would be against the ethical considerations of the patient.

(Field diary, April 12, 2011; edited)

The way the Danish health care system is organised structures how the young patients must arrange their schedules for both a consultation and to have blood samples taken, in correlation with the opening hours of the hospital. Sometimes, it can entail a great deal of waiting; at other times, it takes

²⁴ See prologue.

less than half an hour to get the blood samples taken. The following week, Chris and I meet up again – this time, to go to the consultation with his physician:

We enter the physician's office, and I introduce myself. The physician explains that he has a medical intern who is going to be following the consultation. We sit down at the table. The physician is talking to Chris in English and asks in a friendly tone how he has been. They exchange small-talk, and there is a nice atmosphere. The physician measures Chris's weight on a scale and asks him if he is still working out – and jokes about his good physical shape. We sit down again at a table (the physician and intern on one side; Chris and I on the other), and we look at Chris's journal – his numbers are fine. His viral load is still undetectable. The physician explains to Chris that the hospital has to cut costs; therefore, not all of their patients can remain on the kind of medication he is on – it's too expensive. The physician emphasizes that he will discuss it with the other personnel, and that Chris can most likely remain on his current medication. If it is not possible, his physician explains, then instead of taking one pill once a day, Chris will have to take three pills once a day. It's the exact same medication, just separated into three different pills. The physician asks a nurse, who has entered the room, if she could find the medication for Chris and if they have any left, enough for a month. (...) We leave the consultation room and go to see the nurse, who gives Chris a bottle of pills; she says that he will have to come back for more in a month's time. We talk a bit more and Chris seems sad about the prospect of having to change medication. He explains that he is nervous about it because he has always been on that same medication, and it works really well for him. Besides, he would also have to take three pills a day instead of just one. He says that it is sometimes hard to be HIV-positive.

(Field diary, April 2011; edited)

The previous two quotes from my field diary demonstrate how a *clinical version* of HIV is shaped and comes into being. Chris has to take time out of his day to get his blood samples taken, and then to go for a consultation with his physician a week later. The check-ups monitor “how well” he has taken his medication²⁵, his viral load and what his CD4 count²⁶ is, among other things. As described, the physician is both friendly and engaged during the consultation with Chris; they exchange small-talk and the physician jokes about his good physical shape, which indicates that Chris is taking good care of himself. With regard to the possibility of having to change medication, Chris is both nervous and sad; he is also anxious about how he will react to the change, and if the medication will work just as well as the old one. In our talk afterward, Chris asks me if I think that his physician will keep his promise; i.e., that he will recommend that Chris stays on his present medication, and I respond in the affirmative. It seemed odd to me how little time was spent on the consultation (about ten minutes), and also that there was no time spent talking about Chris's personal life. On the other hand, I do not think his physician did a poor job; he cared in the way he should have by providing good treatment and even recommending Chris to the other personnel with regard to the possibility of medication change. The physician's involvement with his patient was indicated by his jokes, familiar tone and knowledge about Chris. The fact that there was no time to talk in depth about the patient's personal life can be explained both as a consequence of the time allotted by ‘the system’, but also by the ‘expected’ role of a physician, which is mainly to treat the patient. As such, the way that Chris handles being HIV-positive (i.e. his

²⁵ The viral load measures how many virus particles there are in a microlitre of blood. Medication is offered to HIV-patients when their CD4 count is below 350 per microlitre (350 million CD4 cells per litre of blood). When a patient adheres to their treatment (i.e., takes their medication regularly), their viral load becomes undetectable. An undetectable viral load means that the test cannot measure any virus particles; the test can only measure virus particles below a certain level (Laursen et al.: 10-11).

²⁶ CD4 count is a measurement that monitors the amount of CD4 cells in the immune system. A ‘normal’ level of CD4 cells is between 600-1,200 per microlitre of blood (Laursen et al.: 13).

anxiety about a possible medication change) can either be something that the physician expects Chris to take up, or something that there is not necessarily time to address (Jespersen 2007: 105).

This illustrates how a consultation can be organized, and which elements are a part of it: e.g., checking Chris's weight, discussing his viral load and CD4 count, etc. The time spent on the consultation hints at other actors that affect the consultation, such as the health care system – it is involved in the cost of treatment, and thus how much time is spent on a consultation, as well as which medication is offered to patients. Another aspect that becomes apparent is the division of roles between patient and physician, which underscores the responsibility of the chronic patient. As such, I must assume that the reason why Chris's physician does not explain more about the medication is because he expects that if Chris has any concerns, he will ask.²⁷ Feelings (e.g., anxieties, jokes, etc.) are thus part of the consultation, but how they are dealt with, shaped and constructed depends on entities other than just the physician. Therefore, feelings are dealt with both within and outside of the consultation room.

Room for more

One of the other informants, Anna, is part of a project at Skejby where a group of young patients meet up for a day at a cottage outside of the hospital. The participants get their CD4 counts and viral loads tested.²⁸ The following day, they have a consultation about their results. Anna explains why she travels several hours and spends a whole day to do this:

Anna: You have the time to sit and talk to the others and hang out with them. I think that's it, because I had a really good physician and nurse. (...) You get a bit of what the weekend trip affords. I think it's uncool to get one's blood samples [taken at the clinic], and you don't know whether [the nurses] talk aloud – the ones taking the samples. You're sitting next to a lot of different people. (...) I just think it's annoying that I have to go there. I have always gone, so it's not because I've used it as an excuse not to go. I just feel more ill when I have to go there. (...) I would have to take half a day off work anyway, and now I take a whole day. (...) It gives me a lot more than an hour's talk with a physician. (...) We had an incident where one [person] had to start on medication the last time we met. I think it was hard for him, even though he is fine about it now. At that moment, it was so much better that he came back out to us. Then he could tell us how he felt, instead of leaving the consultation and bicycling home [alone]. There was room for more [than that]. Which is great.

(Anna and Nikolaj/ interviewer)

As mentioned, any changes in the medical treatment of HIV are addressed in the consultation. Part of dealing with them (the results) is also done in the consultation, but part is left to the patient. The project that Anna is involved with includes time afterward for the HIV-positives to discuss how they feel emotionally; e.g., about having to go on medication. Anna's comments illustrate the need to have room/time to discuss how one is feeling emotionally as a patient, which is not necessarily something that is always allotted enough time in a consultation. As quoted in the mentioned project there is time after the consultation to sit and talk. The patient is surrounded by other HIV-positives he knows and is not left to handle his emotions afterwards alone. Furthermore, in Anna's case, it makes her feel less ill to go to the project than to a hospital. She also does not have to worry about what the nurses might say out loud. For Chris, that did not seem to be an issue. The nurse would not say anything to me about his

²⁷ I assume this on the basis of Astrid Pernille Jespersen's Phd (Jespersen 2007), which is concerned with the role of the physician. In this study I have not interviewed or 'followed' a physician which is why I write assume.

²⁸ The young patients get tested for other things as well, but I have chosen to focus on these two because they appeared to be the most important ones for the youths.

test – despite the fact that Chris approved – and no one said anything aloud about which tests the patients needed.

Even though the consultations are performed differently they include some of the same elements: the measurement of CD4 counts and viral loads, and sometimes changes in treatment. In the following section, the youths' CD4 counts are explored. The CD4 count is an indicator of the strength of a patient's immune system: The 'normal' level is between 600–1,200 per microlitre, but when it has deteriorated and reached a level below 350 per microlitre, then medication is recommended. A patient's CD4 count is monitored via tests, and it has different meanings to the young patients that change over time.

CD4 count

Anna: Those of us who are not on medication have a competition about who has the highest CD4 count. I'm in the lead – mine is 730.

Ditte: Do you do anything extra?

Morten: I take a lot of vitamins.

Anna: The weekend before, we had to go [for a check-up], and I didn't want to go out drinking.

Morten: I don't pay attention to my CD4 count.

Ditte: Not if it fluctuates?

Morten: Yes. Last time, it was 930 and this time it was 630, and I thought, "Oh no, how awful".

Søren: But you discover [along the way] that they fluctuate. I once had mine measured at 1000, and before that it was 230. Then we took another test and it was 400 and something. We've been told that it fluctuates according to how well you look after yourself.

Morten: I always take my herbal medications, think positively and exercise. I divide it into what is dangerous for the disease, and what isn't. If it's dangerous for the disease that I eat healthily – then that's the drive. I quit smoking a year ago and had imagined that my CD4 count would increase a lot, and when it fell – I thought, "Sod it". The motivation is whatever can bring the development of the disease to a standstill. (...)

Anna: I feel this way – I have to eat healthy and exercise to mentally have the energy to deal with the disease, and that affects one's numbers. I've been asked if I only lead a healthy life, and I don't. But I feel better if I do.

(Ditte/interviewer and Anna, Morten and Søren)

The CD4 count itself is enacted in various versions: It is both a *statistical, calculated norm* that measures the strength of the immune system, and also an indicator that marks when patients are advised to begin taking medication (Mol 1999: 79). Furthermore, it becomes something that the young patients use competitively as an indication of how ill/healthy they are. They also use it as an incentive to perform healthy choices with regard to HIV. At the same time, it is both an incentive toward and a barrier against a healthy lifestyle. Moreover, it can be something unreliable because it fluctuates without reason. In Søren's case, the CD4 count is something that is important to him. But because it is a number that fluctuates, for example, he cannot be too concerned about on his CD4 count.

Double-edged sword

Søren: To me, it's a double-edged sword because I've been at a really critical level with my CD4 count and have had all these weird complications – which is why it means a lot to me. At the

same time, it is weird when you're in a steady relationship, and it [the viral load] can't be measured if a condom breaks. My viral load was very high and my CD4 count was very low when I came to the hospital in the beginning. (...)

Ditte: Was that when you stopped taking your medication?

Søren: Exactly. I stopped with my medication and got ill again – my CD4 count was below 100, and my viral load was so high that they almost couldn't measure it. It happened within six months, and that's why I have respect for the medication.

Anna: The viral load is not something you discuss the physician. If we are not on medication, then we don't get this information – unless we ask.

(Ditte/interviewer and Anna, Morten and Søren)

In Søren's case, his CD4 count was very low in a period when he was not taking his medication; therefore, he enacts the CD4 count both as something extremely important and something that fluctuates, which means that one cannot depend on it. It also becomes apparent how his viral load is performed; if he is well-medicated – that is, if he adheres to his treatment and takes his medication as prescribed – then his viral load is undetectable. If a condom breaks, then Søren says it is weird because the viral load cannot be measured.²⁹ I interpret Søren's comment to mean that to him it feels weird that he does not know how much virus is in his blood – only that the risk of contaminating someone else is low. In a sense, (maybe) it is weird to relate to one's disease when it cannot be measured, especially when another person has been exposed to the disease.

Being on medication

Søren: I'm already on [medication], and have had both negative and positive experiences. I've been on three different kinds of medication. Twice, I suffered from severe side effects, particularly the first time. I got a crazy rash – almost like German measles – stomach cramps almost every ten minutes, vomiting and diarrhea and insomnia. After that, I switched to a different kind – which made me hallucinate, delirious, and I had hot flashes. In regard to the medication I'm on now – it only makes me have very vivid dreams, and in the morning, I sometimes feel tired because I feel like I've been physically present in my dreams. We've been discussing it, the ones who are on that kind of medication – stocnin – and it completely messes with one's head. That's also why they tell you to take it before you go to bed. When I worked as a bartender during the weekends and had to take it at midnight – then two hours later it just hit me, and wow – it was like, pouring pints of lager while my hand felt like it was next to me. (...) There are side effects to all of it, and that's the case for the rest of my life, and I will most likely have to switch to different kinds of medication at least ten times before I die of old age or a cure is discovered. I've experienced what it leads to if I don't take it. I quit after two failed relationships. (...) I told them [I am HIV-positive], and they backed out. I think I went into a phase of denial and quit taking my medication. (...) I had a depression the second time it happened. I experienced how ill I got. It was like my primary infection – I started losing a lot of weight, couldn't eat, couldn't sleep. I know how important the medication is – and I've only missed the medication I'm on now once, which isn't normal.

(Ditte/interviewer and Søren)

Being on medication can involve side effects, and the medication can be of great importance. It becomes something that the youths structure their lives around, and something that keeps them from getting very ill. On the other hand, it can also be something that indicates that one's immune system has deteriorated; thus, it is also something that the youths feel sad about, as described earlier by Anna.

²⁹ If a condom breaks, the non-infected partner has to see a physician at one of the departments for infectious diseases within 24 hours. The physician will determine if it is necessary to start a PEP (post-exposure prophylaxis) treatment. PEP treatment is often used when someone has been accidentally exposed to HIV during sex (Kehlet 2006: 78-79).

As Søren explains, the medication is also something that can make one ill because of the side effects. Here, Søren views the medication as something that structures his life:

Søren: Whether you want it or not, you structure your life around it. It takes me an hour to travel to work, and I have left home without my medication. Then you have to phone and say that you'll be late for work. You have to go back and get the medication because you know that if you don't take it, you risk becoming resistant. That's not a chance I'm willing to take with this medication because it works really well for me.

Nikolaj: What about the two of you – you're not on medication?

Anna: I think I'm ambivalent. There's a reason why I have to take it – it's going to keep me healthy.

Søren: I think there's a difference in being HIV-positive before and after you're on medication. You become more aware that you're ill when you have to take pills morning and evening, following a schedule. And you HAVE to – otherwise, you get really really ill. I found that really difficult in the beginning. To me, it's a question of incorporating it into your life – it becomes a routine, like taking vitamins or brushing your teeth.

Morten: I hope it will be different for me. I've already decided, I think, that I want to start on medication after what I've seen on the news and heard during the Youth Group's weekend trip. That's leaning toward starting on medication straight away³⁰. (...) I get your point, but at the moment, I don't see myself as being ill. (...) I refuse to see myself as ill just because I have to be on medication. So I would rather take [the pills] because a little angel on your shoulder is telling you to do so – "It's a magic pill that gives you magic dust". I'll do anything to not see myself as ill. "You're an HIV-positive on medication" – that's the worst thing I could hear myself say.

(Nikolaj/interviewer, Ditte/interviewer, Søren and Morten)

According to Søren, starting to take medication can be something that is necessary because otherwise he will become ill; at the same time, it makes him feel more ill because it reminds him of his disease, which he does not generally think about very much. Over time, the structure it imposes becomes less obvious; according to Søren, it is something that one simply incorporates into one's life. Søren's case illustrates how much "work" is left to chronic patients; it is not only taking medication and following treatment, but also handling how it makes one feel and how it affects one's life. In Morten's case, he would rather enact the medication as a 'magic pill', in order to refrain from seeing himself as ill.

A partnership for life

Søren: There's a difference. When I started on my medication, I wasn't as strong, and I didn't have a close bond with the others in the Group. I hadn't come to terms with it. I think there's a difference in whether you are thrown into it with a strong or a weak psyche. I don't think that you'll feel the same way when you start on medication.

Morten: I've said that I'll start on medication when I'm ready. You probably never get ready, but I will say: "Medication, come to me" instead of "You have to take medication or die!" That's why I think that I'll take the first step in a partnership that I will have for the rest of my life. We have to communicate well and make the most of it. I don't want the pill and I to be enemies.

Søren: I don't feel that way anymore; now, it just happens automatically, and it isn't something I think about. I thought a lot about it for a while, but I don't anymore. There are still times when it's annoying. If I'm traveling, I have some good friends in London and Berlin, and I keep my medication in my toilet bag. I don't travel with a medication passport, and there's a fear of getting stopped.

³⁰ Part of the weekend trip includes a session with a physician, who explains what changes have occurred in the treatment of HIV and outlines any new recommendations. During the 2011 trip, the physician said that the treatment of HIV was changing, and that medical research indicated that it would be better to start on medication immediately after being diagnosed instead of waiting until one's CD4 count reaches 350 per microlitre or below.

(Ditte/interviewer, Søren and Morten)

It is clear that medication is enacted in many different ways; in addition to the performances already mentioned, it can also be an annoyance and something that one is afraid of being discovered with while traveling. This is why Søren hides his medication when he travels.

The ultimate solution

For some of the youths, medication can be performed as ‘the ultimate solution’, as seen in the next quote:

Jonas: When I got diagnosed, my CD4 count was 750.

Ditte: That’s within the norm, right?

Jonas: It’s very common. Then this summer, it had dropped to about 400, and I was asked whether I would be interested in taking medication. I would have to start considering it, and then I could start after the summer vacation. I said that I might as well begin if that’s the way it was heading because there was no reason to wait. Right from day one, I’ve questioned why I didn’t need any medication. I couldn’t understand why I’d have to wait to be “sick enough” to start doing something about it. I would rather take the greater risk of getting a blood clot than having that much bacteria in my body. Because I simply don’t think that it’s good – I don’t think that it’s healthy for my head to be filled with the virus. To me, [medication] has been the ultimate solution. Someone like me should just have been handed the medication from day one. (...) In connection with my relationship, it’s been worth its weight in gold. I feel like I want to have sex now. I can imagine wanting to have sex, even if I was single. I could even engage in sexual contact without telling people – because I know what my numbers are. And I know that the risk isn’t there at all.

(Ditte/interviewer and Jonas)

Here, Jonas views the medication as a form of protection; taking it means that he is not as worried about infecting his boyfriend. In that connection, the medication has been ‘worth its weight in gold’. He can even imagine having sex if he was single, which is something he would not have done prior to taking the medication. To Jonas, being on medication is something he performs to keep the virus at bay. Waiting to ‘be sick enough’ to go on medication seems worse than the potential risk of developing a blood clot from the medication.

Summary

In the previous pages I have investigated how HIV appears in different versions and how this affects the lives of the young HIV-positives. I focused on the enactment of HIV. Before the youths have been infected with HIV they do not necessarily know how far the treatment of this chronic disease has developed, therefore they think that they are going to die or that they can never have children. They initially have to get around the idea that they are HIV-positive. This information becomes available through consultations at the hospital or at their regular GP. After this initial chock many of the young patients choose not to tell a great deal of people. This implies that they are left to handle being ill on their own outside of the treatment facilities.

Living with HIV includes new medical entities such as medication, CD4 count and viral load- all become part of their lives. How to live *well* with this disease becomes a difficult question to answer. Each element has several different implications, thus being on medication is not just one thing - it is several. On top of this ‘feeling ill’ change over time and not in a linear fashion progressing and ending at the perfect solution. Instead the movement can be back and forth, therefore managing a disease is a

continuous work, which requires a lot of effort and time from the youths both in and outside of the treatment facilities.

Chapter 3

Stigma and social ordering

In the previous chapter, I closely examined how HIV was enacted at the general practitioner, over the phone and in the outpatient clinic within a hospital setting. I analysed how the diagnosis of HIV took place and how elements such as medication, CD4 count and viral load became part of the young patient's lives. It illustrated how HIV is a multiple disease enacted in many different versions. In this section the analysis still focuses on performances of HIV, but it moves into the youths' social lives; where HIV can be a secret - something that is withheld from others, accidentally discovered or something that is only shared with one's partner and family. As such, this section focuses on how 'the social' can be organized and framed from both a theoretical and an empirical point of view (Law 1994). The centre of investigation, in this part is two fold, first I explore the concept of stigma which is based upon the youth's fear of rejection and how this fear affects their lives. These (fearful) situations are connected to work, education, living arrangements and the youths' relationships with boyfriends, girlfriends, friends and family (or one-night stands). Secondly, I define three different modes of ordering (Law 1994) which I view as different versions of HIV. These versions are: silence, openness and karma. These modes can be characterised as patterns or logics, which can be imputed to the lives of the young HIV-positives. Each version is a hybrid between theory and empirical data (Law 1994: 9). I thus hold on to my point of departure of viewing HIV as a multiple disease performed in several different versions (see introduction).

First I describe the concept of stigma, which is followed by a description of the three modes of ordering -both are then utilized in analysis of how HIV affects the youth's lives outside of the hospital setting.

Erving Goffman

Erving Goffman wrote about stigma and conceptualised the subject matter in his book *Stigma and Social Identity* (1963), which proposes a sociology of deviation. In this part of his work, Goffman focuses on the construction of normality and deviation, and its wide-ranging effects. Goffman explores and conceptualises how stigma occurs, and how it is part of the micro-processes of everyday lives. His concepts have greatly influenced how stigma has been analysed and understood because he framed how stigma could be captured (Harris 2009; Goffman 2009: 12). Today Goffman's work is still valid, despite the profound changes in society since his book was first published. This is underlined by its applicability in this and other studies (Goffman 2009: 10). As such, Goffman's sociology of deviation can be conceived as timeless because it is concerned with fundamental topics, such as the fear of being revealed and the fight for recognition, this also explains why it is used today (ibid.).

Identity

According to Goffman, identity is something that is not given by nature; agents do not have an essence. Identity is neither constant nor unchangeable; rather it is something that can be destroyed, offended or constructed/created. A critique against Goffman has been raised for producing "individual tragedy", rather than a shifting, and often resisted, social process" (Harris 2009: 37). The individual is a result of the interaction in which s/he takes part (Goffman 2009: 13). According to Goffman, society is held together by interaction between people and the keeping-up of 'face work' between either strangers or acquainted individuals. The rules of interaction are what constitute society, and as such, negotiations of interaction and the definition of different social roles are analysed (Sandberg 2009: 51). The centre of investigation is thus social roles and relations between people; materiality and its agency, however, is not part of the analysis which is a significant point of departure for this thesis. I refrain from viewing

stigma and society as constituted only by interaction but perceive them as effects of socio-technical ordering, and furthermore I refrain from utilizing different social roles. How HIV appears and affects the youths is effects of socio-technical ordering within which stigma also can occur.

Stigma

Stigma can be traced all the way back to the ancient Greeks (...) who devised the term to refer to bodily signs that would indicate or reveal something unusual and bad about the bearer's moral status. The signs were either cut or burnt onto the body and thereby proclaimed that the bearer was a slave, criminal or traitor — a tainted person, ritually defiled and who should be avoided, especially in public places.

(Goffman 2009:43, my translation)

Since its noted beginning in Greece, stigma has had another two layers of meaning added: The first one is red marks as an indication of bodily signs of Holy Mercy; and the second one is a medical allusion where bodily signs or markers indicate illness. Today, stigma defines the disgrace, rather than the bodily signs defined by Goffman (ibid.: 2009: 43). As such, stigma arises when two people interact; if one of them does not recognize the other and judges the person because of a stigma, the stigmatized thereby becomes discredited. In situations where there is a potential for the individual to be revealed, Goffman describes them as potentially discreditable. Goffman defines his concepts as discredited and potentially discreditable, which I find to be old-fashioned and foreign in my vocabulary; because of this, I use the terms *not recognized* as a replacement for discredited and *potentially revealed* as a substitute for potentially discreditable. These two concepts are more current and explanatory in relation to this thesis (albeit perhaps not the most elegant choice), and thereby they make Goffman's concepts more current. One of my informants, Søren, describes how he has experienced being not recognized, and how people have rejected him after he disclosed his status. In this quote, he talks about relationships:

Ditte: Have you had some bad experiences telling other people who have not been worthy of your trust?

Søren: Yes, twice in a row, when it was people whom I was on the way to being in a relationship with. When I told it, they [said]: “Back off”. (...) At that time, I was convinced that I would never have a boyfriend or girlfriend again.

(Søren and Ditte/ interviewer)

In this connection, Søren was rejected and discriminated against by two potential partners, and stigma was performed because Søren was not recognised. Experiences such as these have great impact on the youths' lives. Stigma is defined as a lack of recognition, but is further conceptualised into three different kinds. Goffman identifies them accordingly:

“First there are abominations of the body – the various physical deformities. Next there are blemishes of individual character perceived as weak will, domineering or unnatural passions, treacherous and rigid beliefs, and dishonesty, these being inferred from a known of, for example, mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicidal attempts, and radical political behaviour. Finally there are the tribal stigma of race, nation, and religion, these being stigma that can be transmitted through lineages and equally contaminate all members of a family. In all of these various instances of stigma, however, including those the Greeks had in mind, the sociological features are found: an individual who might have been received easily in ordinary social intercourse possesses a trait that can obtrude itself upon attention and turn those of us whom he meets away from him”.

(Goffman 1990 (orig.1963):15)

In connection with HIV and AIDS, it is character traits that are at stake, but physical abnormalities can also be part of AIDS; e.g., when the patient's body starts to show bodily signs of illness (ibid.). But what has fuelled stigma of HIV-positive, and what makes the infected appear to be less of a person than the non-infected? (Mik-Meyer 2009: 124). In order for an individual to be judged, 'society' exerts ways to categorize people, which are based upon certain values and attributes that are perceived as normal and natural. Through denouncing HIV-positive people, it becomes possible to view them as something 'other' than the non-infected; e.g. something outside the norm. The judgement is based upon people's expectations, and according to Goffman, when we encounter a stranger, we will most likely be able to place that person in a category, which enables us to predict what kind of person s/he is (ibid.: 43-44)³¹. These initial impressions are converted into normative expectations or even just requirements (ibid.); therefore, they should instead be characterised as demands to be confirmed at later observation (ibid: 44). The common denominator for stigma is that it entails a negative judgement when a person deviates from society's expectations or assumptions, whereby different kinds of discrimination are exercised (ibid: 44). There is a discrepancy between the virtual identity; what people expect and the actual identity of an individual (ibid). Discrimination is apparent in Søren's case, where he was stigmatized because of his disease.

Modes of ordering

John Law's book *Organizing Modernity* (1994) is an early contribution to the multiplicity oriented ANT and is part of the performative turn (Sandberg 2009: 53). In this book, Law analyses how management and the organisation of the British Daresbury SERC Laboratory is performed. Through 'thick descriptions' of the laboratory, Law illustrates how Daresbury cannot be described, understood or reduced to only one thing, instead the laboratory 'exists' in plural e.g. in different versions. Law constructs a novel concept which he characterises as modes of ordering and each of these are a separate version of the perfect agent: what agency is and what the organization should be (Elgaard Jensen 2001: 73). Law's investigation is centred on socio-technical orderings and like Mol, Law defines the social as "materially heterogeneous; talk, bodies, texts, machines, architecture, all of these and many more are implicated in and perform the social" (1994: 2). Management and their strategies are therefore effects of the socio-technical ordering e.g. an agent etc. is an effect of the socio-material network. These orderings are precarious and partial. Thus the different modes require continuous work and can be overturned (ibid.).

The four modes are identified as: enterprise, administration, vision and vocation (1994: 73-86) and can be characterised as:

"Fairly regular patterns that may be usefully imputed for certain purposes to the recursive networks of the social. (...) They are recurring patterns embodied within, witnessed by, generated in and reproduced as part of the ordering of humans and non-humans relations".
(Law 1994: 83; Elgaard 2001: 73)

In this connection applying Law's construction of modes does not make sense as they are not recognizable in my empirical data and do not reveal patterns that can be imputed to 'the social'. Following my point of departure and aim to define and view HIV as multiple and existing in different versions, I view a mode of ordering as a version of HIV. Versions of how the HIV-positives actions and talk can be written into different patterns. The modes of ordering are connected to and affected by discourses, legislation, sex education in public schools, media representations of HIV, prevention

³¹ Goffman focuses on meetings between strangers, but in this case, it is interaction between individuals that is at stake. It can be between the youths and strangers, relatives, friends or partners; it is any kind of interaction that involves a stigma in this respect.

schemes, definitions of risk groups, and policy documents. Besides this they are shaped by how the youths perform, talk about and tell stories about HIV. A mode of ordering is thereby a hybrid between theory, mini discourses, stories, histories and empirical data (ibid.: 9, 74 & 83). Each mode is recursive - it is self-generating and there is nothing outside of or behind it which affects the process (Law 1994: 15). Each mode is a summary of characteristic traits, and for the particular mode of ordering it identifies what a perfect agent is or should be; it constructs patterns of the social. The three modes are therefore ideal types and should not be understood as personality types (ibid.: 74), I have named them silence, openness and karma. In the following I first sketch out the three modes of ordering and then utilize them in my analysis. I furthermore combine them with the concept of stigma. The two different concepts; stigma and modes of ordering, underline the immense effect stigma has on the HIV-positives and the three patterns show under which circumstances a particular agency is appropriate.

Three modes of ordering

In the ordering mode *silence*, HIV appears as something which is a sensitive matter; it appears as a disease that you do not tell people about. HIV can appear as something you are ashamed of. This mode furthermore establishes HIV as a disease the HIV-positive is responsible for being infected with or something they could have prevented. HIV is connected to specific risk groups such as gay men, prostitutes, people who have many sexual partners or people from a country or state in Africa. The different elements that HIV is ordered by appear in a very negative light.

The perfect agent is someone who is good at keeping HIV a secret, someone who is skilled in telling lies, keeping track of who s/he told what. Within silence covering up any information in connection with HIV is seen as a quality e.g. quickly coming up with an explanation if someone is about to blow ones cover. Control and keeping track of things are virtues in this respect. When HIV is ordered along silence, all the effort and time spent on covering up, hiding medication and keeping HIV a secret appears as 'the right thing' to do and is a means for the youths to keep HIV a secret. The acid test is controlling knowledge of your HIV-status and performing all the necessary tasks to keep it that way.

The ordering mode *openness* is in opposition to silence and entails telling people about the disease and therefore not having to worry about keeping secrets, telling lies or hiding ones diagnosis. HIV appears in this ordering mode as a chronic disease like any other, something you can share with people. HIV is just a diagnosis you have - it is not who you are. HIV is not necessarily seen in a negative light but rather as something you deal with. The perfect agent is someone who is not afraid of or worried about sharing their diagnosis, someone who is capable of sharing their status without fearing repercussions. It is someone who refuses to hide their HIV-status from others. Being able to explain and tell people about HIV is seen as a virtue. The means to do this, is telling others and expecting them to pass this information on, being open about appointments at hospitals, medication and changes in CD4 count, viral load or other information about the disease. The acid test to openness is not hiding one status and being open about the disease.

Karma is the third and final mode of ordering, this mode is connected to the opinion that you should treat others like you want to be treated. Karma is mainly shaped by the fact that HIV is a contagious disease and that it can be transmitted sexually. It is for that reason a disease that you at some point have to tell your partner about. Karma is concerned with who you should tell that you are HIV-positive and when. This mode of ordering is connected to the fact that the HIV-positives have been infected by someone; someone who did not give them that choice or considered the possibility that they would have liked that choice. The perfect agent is someone who gives other people the opportunity to not get involved with a HIV-positive. Someone who shares that they are HIV-positive at some point. The perfect agent is someone who treats others as they would like to be treated themselves. The means in this mode is informing others about one's HIV-status before getting sexually involved or before getting

too serious (in connection with relationships). Karma also speaks of moral, that the right thing to do is to tell people you are involved with, that you are HIV-positive.

Exploring stigma and modes of ordering

As mentioned many of the young HIV-positive keep their status a secret from most of the people they know - even relatives. This indicates how difficult it is to be HIV-positive in Denmark because it is still a disease with taboo and stigma attached to it (Kehlet 2006: 50-53). Because of this, a mode of ordering in relation to HIV is silence. The questions concerning who and when you should tell can entail a great deal of effort, time and emotions, such as fear and anxiety -which is where both silence and karma are applicable. Most of the young people I spoke to told their most immediate family and their closest friends; an exception is one man who lived openly with his HIV-status for quite some time. There are many reasons behind choosing to tell others, which are connected to sexuality, control, trust and fear, to mention a few. When the youths keep the disease a secret, other aspects of their lives become affected by this decision. One of my informants, Chris, is from a country in Africa; he moved to Denmark in 2009. He only discloses his status to his closest friends and to his sexual partners. In this quote, he describes how he feels about keeping HIV a secret:

Chris: Actually, I am fine with that. Now I think: If I tell people, what does it make me? I don't feel the need to – if I am not close to you, I am not going to tell you, but all my best friends or good friends know. Sometimes we joke about it, “Hey, remember I have HIV – don't hug me”. But I don't go to Strøget³² and say, “Hey, I am HIV-positive”. It's hard to open up to people because I feel like people feel pity for me, or they will look like, “Oh, this guy is HIV-positive”. Yeah, I was scared of rejection. People pull back.

(Chris)

As indicated, telling people that one is HIV-positive is not an easy task; in doing so, the young people set themselves up for being both not recognized and potentially revealed. They do not know how other people will react to their disclosure which is when silence generates their actions. Furthermore, when they have told a friend, they risk that this information is passed on to others. As described, some only tell their closest friends and family. As Chris says: “I don't feel the need to”, so for him, it is not necessary to tell people unless they are his closest friends. Chris also mentions that he and his friends joke about HIV: “(...) I have HIV don't hug me”. As mentioned, HIV is an infectious disease, and some people view HIV as extremely infectious. The infected can be seen as ‘untouchables’ because people fear being infected by touching them; this resembles opinions about people with leprosy, who were/are seen as extremely infectious (Harris 2009). This illustrates how silence orders HIV and the agency of HIV-positives. In connection with silence stigma and the fear of it greatly affects or mobilises this mode of ordering. One of the problems that the youths face is that sharing their secret also makes them vulnerable, because their confidante might not keep the information to themselves. When the youths mainly are ordered by silence then not keeping their secret intact means a breach of confidence.

Chris: I don't feel like telling people because then it's going on and on...and you never know who knows. I will be really happy and feel better if somebody knows because I told the person – this way, I will know it is from me.

(Chris)

³²Strøget is the main shopping street in Copenhagen.

When HIV is not kept a secret, the youths no longer have complete control over the information that they share with a friend; they are relying on their confidante to keep the secret. Besides this Chris says he ‘will be really happy and feel better’ if he tells people about his disease. When one of his friends do tell others Chris feels betrayed.

Openness

As mentioned, not all youths keep HIV a secret; one of my informants has been open about being HIV-positive. In this respect, the lack of control over who knows is performed in an altogether different way:

Morten: I have lived quite openly with it and still partly do. I am pleased now that I have been so open about it before because now everybody knows. Now I don’t have to take it into consideration: Nobody knows – so now I have to tell it. I am very glad that I have been a pig with my mouth – it sounds wrong, but I just told everybody I met because I just wanted them to know. (...) It’s very much immortal teenage years. (...) And of course, the ones I told couldn’t keep their mouths shut, and I haven’t minded that. I have also told them: “I am fine with it”, and that has also been an acceptance for them to tell other people. I have made them do all the preliminary work, which I think is so clever.

(Morten)

As Morten explains, he decided to be open about HIV and made it work for him because his friends told others: He has “made them do all the preliminary work”. In this case openness structured how HIV was performed. As this quote illustrates, openness for Morten meant not having to worry about people keeping his secret and getting other people to pass on the information. Today, Morten’s actions are ordered along silence, openness and karma. Morten mainly keeps HIV a secret in connection with work. Being ordered by a specific mode is tightly connected to other people’s reactions and the effect this has or might have or when the youths think they have to tell other people e.g. mainly in relation to partners. When silence structures agency, passing information on about a HIV-diagnosis is viewed in opposition to openness. Thus, Chris had a completely different view on when his friends were not able to keep a secret. He describes an incident:

Ditte/interviewer: Have you had any bad experiences where you told somebody and they told somebody else?

Chris: Yes, I told someone. I was really disappointed because I was thinking, “Danish people know how to keep secrets – better than we blacks.” This girl was travelling to xx [a country in Africa] with another girl, and she said: “Do you know anything about Chris? Because he is so involved with HIV things”. And she said: “Oh, he is HIV-positive”, while they are sitting on the plane, and this girl even said: “I don’t even know him that well – we just met and said hej, hej³³”. Later on, she felt awkward, so she told one of my best friends, and he told me. She really needs to apologize to me.

Ditte/interviewer: Did she apologize to you?

Chris: Yes, she called me from xx [country in Africa] and said she was really sorry, that it just happened. So I was really disappointed. She should have said, “Just ask him if you want to know something”, and she said: “We Danish people don’t lie, and she was looking at my face and my eyes, and then I couldn’t lie”. [And I said,] “It wasn’t your business, honestly – it’s mine”. But it was already done, so we couldn’t do anything about it, and now we keep a distance from each other. Recently, the girl I am dating now – someone told her before I even got a chance to say it.

(Chris and Ditte/interviewer)

³³ Hej means hello in Danish and in this respect it indicated that the girl and Chris are just acquainted, not friends.

Silence: caught in a spider web

When HIV is performed as a secret, it can necessitate other actions. For example, when the young HIV-positive has not told family or friends that he/she is HIV-positive, how do they then explain going away for the annual weekend trip with the Youth Group? Or when they have to take a day off to go to the hospital for a check-up?

Anna: I can't just say that I need time off – then you have to come up with some odd reason for why I need the time off, and I didn't even have to come up with a reason. I just had to say that I needed a day off, because you are entitled to them, even if you just want to relax for a day. But then something funny comes out of your mouth.

Søren: I think we have discussed this before – then some defence mechanism, you don't even know where it comes from, but something just pops up, and you catch yourself thinking, simultaneously as the words pop out of your mouth, "What on earth are you saying?"

Anna: Yes – "Why did you say that?"

Søren: Just because you are so used to it. Then automatically you respond like that because you live so closed with it. They're defence mechanisms. That's what it really is.

Anna: I have never been caught in any of those lies.

Søren: Me neither.

(Anna and Søren)

The fear of being discovered involves an overemphasis on having a good or valid explanation for why one needs a day off, or where one is going away for the weekend. For the youths, it feels as though it is necessary to explain mundane things, such as taking a day off, which do not ordinarily require further consideration; or they feel that they need to have an alternative explanation at hand. Anna and Søren both have the experience of saying something random as an explanation, and at the same time, realising that it is unnecessary.

Silence: a great liar

As mentioned in the description of silence, being able to come up with a valid explanation, keeping track of what other people know and making sure they do not know you have HIV is part of how the youths act. Another strategy to keep people from finding out is telling lies. The youths thus become great liars or skilled in telling white lies:

Anna: You somehow get really good at it [lying] – frightening enough, because you say one thing to your... [family] – well, it is only my closest relatives who know – another thing to someone else, and a third thing to your friends. Maybe you say to your friends that you are in Jutland visiting your family, and to your family you say that you are visiting some friends in Jutland.

Søren: It is immensely stressful, I think. In many ways, practice makes perfect – you get better and better at it. I don't even have to lie – you just avoid the truth instead, so to speak.

Anna: I also think that, even though you lie, then I think that they can tell right away that I am going on a weekend trip with the Youth Group – that's what I think right away. But they just assume that what you say is true, so they don't really question it. But it is frustrating and annoying that you have to lie.

Søren: There were a couple of people in the Youth Group who got caught, where the lies exploded in their faces. They said one thing, and then they said another thing to some other people, then their paths crossed somehow, and they discovered [it and thought], "What has he or she been up to?" That's the thing about keeping track of a lot of things. Who was it that said: "It's kind of like having a spider web, and then keeping track of where they are in the web all the time."

(Anna and Søren)

Even though telling people that one is HIV-positive might not entail stigma, the fear of rejection is closely connected to how the youths act. Acting in accordance to silence or openness is closely connected to stigma, rejection (not recognized) and fear of being rejected (potentially revealed). In Søren's case, it took him nearly a year and a half to tell his closest family; by keeping HIV a secret to some but telling others, the youths find themselves "caught in a spider web", where they have to remember what they told to whom. Keeping things a secret can also result in an exaggerated sensitivity or slight paranoia, because it feels as though everybody can see that they are lying and know that they are in fact going away with the Youth Group. Furthermore, one's skill in telling a lie improves along the way; it becomes less of a problem, and they find ways to make it easier, as in Søren's case. Silence is difficult because it necessitates white lies, which is something that is annoying or irritating to have to do. It is something the youths do to avoid being not recognized - they are situations where Søren and Anna are potentially revealed.

Relationships and one-night stands

Other situations that are experienced as difficult are of a more intimate nature. As an HIV-positive person, one has to decide when to tell potential boyfriends or girlfriends. And what happens if one has a one-night stand - is one obliged to tell the other person, and when and how does one deliver this sensitive information? In this connection silence and karma come into play and when the youths act in accordance with either silence or karma it illustrates what pushes them in one direction or the other.

Nicolaj/interviewer: Do you think that there have been situations where you felt inhibited somehow – where it is the disease that has influenced what you have done and what you have not done?

Søren: For me, lots of times.

Nicolaj: Can you mention a few examples?

Søren: Yes. When you get involved in a monogamous relationship, it may sound ridiculous, but it is the fear of having to have that conversation: "There is something you have to know, blah, blah". That has kept me from it.

Nicolaj: Monogamous relationship – meaning to be in a relationship, or going out with [someone]?

Søren: Yes, being in a relationship with [someone] and trying to build a life together. I just kept putting it off, because who on earth would want a HIV-positive [partner], right? I actually did that for a long time, three or four years after I got the diagnosis, where I consistently thought: "It's just not going to work".

(Nicolaj/Interviewer³⁴, and Søren)

In connection with moving forward in a relationship or being serious about a potential partner, the possibility of rejection and the fear of it greatly affect the youths; they do not want to risk rejection by a loved one. In Søren's case, he did not engage in a relationship for several years; the fear "just of having to have that conversation" made him refrain from it. Initially Søren follows silence and his actions and intentions are affected by his fear of rejection e.g. being not recognized. When he is in a relationship or on the way towards it he feels that he has to tell his partner. Moving towards openness is a struggle, something which is not easily done. It can also be affected by previous experiences. In this regard karma also comes into play because in connection with a partner the youths feel that they have to tell

³⁴ Nicolaj was a Master's student who was also writing his thesis about adolescents and HIV; we conducted a group interview and a design game together, we furthermore both participated in the weekend trip. All these activities took place in October 2010.

them that they are HIV-positive at some point. As Søren explains later, he had been rejected after having disclosed his HIV-status, and thereby had been stigmatized.

Ditte/Interviewer: Have you had some bad experiences telling other people who have not been worthy of your trust?

Søren: Yes, twice in a row, when it was people who I was on the way to being in a relationship with. When I told it, they [said], “Back off”. Then those two, nearly three, years went by. At that time, I was convinced that I would never have a boyfriend or girlfriend again.

Ditte/Interviewer: What about in connection with friends you have told?

Søren: I have not told that many.

Anna: Me neither.

(Ditte/interviewer, Anna and Søren)

Later in the interview, Søren comments on how it felt to be rejected and not recognized by people with whom he was emotionally involved. At this point, the interview is focused on whether one should tell a one-night stand that one is HIV-positive, or whether one should not. In this context, Søren refers to his experiences with his potential boyfriends/girlfriends³⁵. The talk about one-night stands also reveals other moral considerations for the youths:

Søren: You could say that – that is the question, whether you should tell a one-night-stand or not, and in the Youth Group, this has really parted the waters to a great extent. I was on board your ship, until I experienced [being rejected] twice in a row, where I really cracked up. The second time, it took me two weeks just to get out of bed. I was so upset that I couldn’t do anything, and then I decided that I wouldn’t put myself through that again. And I have simply kept it a secret since then, and when I have been with people, I have made sure to use protection. At that point, I was in medical treatment, and my load [viral load] was so low that I could not infect anybody. They haven’t been able to measure the viral load in my blood. But it has really also been a moral dilemma for me – but I have also been able to feel that if I did this [got rejected] one more time, then my life would capsize completely.

Morten: Couldn’t it be because you were more involved with those two who said no?

Søren: Yes, of course, but it will affect you when you open up to somebody. It is just that – that rips your heart out of your chest, and [you] put it out there, and then you are stabbed with a knife twice in a row.

(Morten and Søren)

In connection with two relationships, Søren has experienced being stigmatised, which has greatly affected him. Even though morally he does not feel that he should have a one-night stand without being honest and open with his partner, his experiences have led him to perform HIV differently because otherwise his “Life would capsize completely”. In connection with acting in accordance to silence or karma, being on medication and experiencing stigma has led Søren to act in accordance to silence. He did not share his diagnosis with his partners, because he could not emotionally cope with not being recognized again. Similarly, Anna has also been afraid to enter into a relationship:

Anna: ...It also took a really long time – almost a frighteningly long time before I was with somebody sexually, because I was so...I couldn’t tell anybody, because I thought it was such a big thing to tell. Plus, you can’t really wait forever if there is [someone you like].

(Anna)

³⁵ Søren is bisexual and has therefore had both girl- and boyfriends.

Here Anna refrains from being with somebody sexually because she could not handle having to share this fact about herself. And furthermore it kept her from moving forward in this connection. Anna has also experienced a situation where the condom broke, and in this case, she had not told her partner that she is HIV-positive.

Anna: I was with someone – there was an exception, where I was with a guy without having told him. Then afterward, I discover – I was told that the condom had broken [...]. When he came into the hospital, he was asked whether he had been with an African. “No, I haven’t.” “Then why do you think you have been infected?” “Oh well, because I have been with a Danish girl who knows she is HIV-positive.” “Oh, you haven’t been with an African?” “NO...”

Nicolaj: You said that it was an exception that the condom broke, or...?

Anna: No, the exception was that I – I don’t think you should have. I would prefer that, before you are sexually engaged with someone, then I think you should have the choice to say: “I don’t want to be with you.”

(Nicolaj and Anna)

Here, it becomes apparent how the definition of risk groups affects the perception of who are “the HIV-infected” - in this case, the personnel at the hospital do not understand why it is necessary to perform a PEP test (see page xx) when Anna’s partner had not been in contact with either a person from or who had travelled to Africa and therefore could not have been exposed to HIV. In connection with the discussion about one-night stands and relationships, the adolescents’ opinions about whether one should or should not tell a one-night stand that one is HIV-positive becomes apparent. Both Anna and Søren feel morally that they should tell sexual partners about HIV but sometimes refrain from it because they are afraid of rejection or having “that conversation” (silence). They both feel that the other person should have the choice not to be with them (karma). However, this is a topic that is not necessarily easy to handle, and it might interfere with consideration of the youths’ own well-being.

Karma

Anna: I think it is important that you do tell – also to avoid the condom breaking, and it always does when you don’t want it to. Then I really don’t want to be lying there with somebody – even though people say that you can have one-night stands, I just don’t think it is great to be lying there in the middle of the night with somebody you don’t know: “Sorry, we just have to go to the hospital to get a PEP test.”

Morten: [sarcastically] No, I will tell him in the morning. [Informants laugh]

Anna: I actually think they should have the choice to not be with you, if that is what they want.

Ditte: How do the rest of you feel about it?

Morten: Exactly the same – otherwise, I would not have been infected. The guy who infected me, he knew that he had it, which made my story a bit weirder, and we lived together for six months. I asked him whether he had HIV, and he said no. I can follow [the point] – that you should have a choice, and regardless of how big a hurdle it is for me to tell [somebody], then you need to tell it. If the condom breaks, then it is just twice as bad having to tell it. Then you can be completely sure that you will get a rejection. Put yourself in that position.

Anna: I think it is important to turn it around and say [something]. I would have liked to have that choice, but I don’t think this guy knew at all (*indsæt fodnote*). But I think if I had not been infected myself, and I met somebody who was HIV-positive, then I think I would have liked to have the choice and just think about it and say: “No, that is not going to work” or “Fair enough.” And I often think that you should do what you would like for yourself.

Nicolaj: The thing about treating others like you would [want others to treat you].

Anna: Yes.

Søren: The good karma rule.

(Ditte/interviewer, Nikolaj/interviewer, Morten, Anna and Søren)

In connection with relationships and one-night stands, the youths might have to perform HIV differently than they initially thought they would, which Søren's experiences illustrate. In his example, being on medication makes it easier for him to not tell a partner because the risk of infecting somebody is very slim. In this respect, the medication acts with and is part of how HIV is performed. As described, the youths' own experiences are connected to their opinions about whether or not they should tell a one-night stand that they are HIV-positive and even though they feel that they should tell (karma) they often do not (silence).

Summary

In the previous section I have focused upon the social lives of the youths and what it means to be HIV-positive in this connection. Here HIV (sometimes) becomes something other than the chronic disease it was in the analysis of the clinical version of HIV. It is a disease that is, most of the time, not visible to the naked eye but keeping HIV a secret or being open about the disease – is not easy. When the youths tell other people about being HIV-positive it can be an attribute which has strong connotations and they thus experience being rejected. This one attribute becomes more important than all other things. Stigma appears as a factor which affects the lives of the youths even if they have not experienced it themselves. It illustrates how being *not recognized* and *potentially revealed* are part of the youth's lives. The three modes of ordering served to underline in which situations silence, openness or karma structured the agency of the young patients. The different modes ordered not only agency but also what HIV appeared to be. Sometimes it was seen in a negative light where silence became applicable. This mode proved tightly connected to stigma and entailed a lot of work in keeping HIV a secret e.g. lies, anxiety and control mobilised 'the perfect agent'. In other connections openness appeared and HIV was thus ordered as a chronic disease which 'you' talk about and do not have to worry about- it was not the only attribute of importance. Karma showed how in connection with partners or girlfriends and boyfriends it was important to tell them about one's HIV-status at some point. One could not wait forever. At other times the youths own well – being made them shift from one mode to another – from karma to silence or the other way around. In the previous summary I explained the continuous work of the youths in relation to their treatment; here the work, effort and feelings are connected to their social lives.

In the next section I focus on the Youth Group which provides the young HIV-positives a space to deal with being HIV-positive and being open about the disease. What this entails will be explored.

Chapter 4

HIV – a gift?

The Youth Group has a unique approach to how one can live with HIV. In this particular setting, HIV can appear as a gift – and this is a somewhat provocative statement because how can a chronic disease be a gift? To describe and analyse this topic, I follow the biases of the Youth Group and engage in writing a eulogy³⁶ about how HIV and the young participants *pass through* this setting. To enable this, I position myself in favour of the premises that have been established, such as viewing HIV as a gift. This inspiration seems appropriate after having participated in the annual weekend trip and interviewing informants about the Group. During the trip, I experienced the affection, kindness and positive atmosphere among the participants, coaches and caretakers; therefore, it seemed like an obvious approach to explain what occurs within this setting. I thereby refrain from applying a critical approach; I could have done this, but it would not have illustrated how HIV can become a gift, and how the participants emerge with new capacities afterward. Instead, this specific approach allows me to show how it becomes possible to view HIV as something positive – which is a unique accomplishment. The following section explores the theoretical point of departure and the analytical concepts that I apply, which are inspired by a study that Emilie Gomart conducted. I utilize Gomart's specific position in my analysis of the Youth Group and its annual weekend trip. The Youth Group's approach was initiated by its two founders, Tinne Laursen and Lotte Rodkjær, but part of it was developed by Hawk of the Yellow Wind³⁷. This section thus explores how the Youth Group performs HIV within the setting of the annual weekend trip. These practices will be framed as a *dispositif*: a set-up that transforms how the young people perform HIV, and which also changes their attitude toward the problems they experience in connection with being HIV-positive. As such, the weekend trip *induces them into action* and enables them to emerge with new capacities.³⁸

Surprised by Methadone

In the article *Surprised by Methadone: In Praise of Drug Substitution Treatment in a French Clinic* (2004), Emilie Gomart investigates how a single clinic in France constructs a different definition of the relation between drugs and addicts, which in turn allows her 'to be surprised by Methadone'.³⁹ Gomart's point of departure is French addiction treatment in the mid-1990s, which at the time could be divided into two opposing views. One group of specialists was against the use of substitution drugs in the treatment of drug addicts, and the other group (the Blue Clinic) was in search of a new treatment approach for drug addicts. Underlying the debate were two very different views of human agency and addiction (Gomart 2004: 85). In Gomart's etymological definition, *addiction* is:

³⁶A *eulogy* can be a speech in praise of someone who has died, or a piece of writing that contains high praise of a person and his/her qualities. In this respect, I am writing in high praise about the Youth Group and its qualities; therefore, I am writing a eulogy.

³⁸ I do not claim that *all* the participants at the weekend trip were *induced into action*, but for the ones I interviewed and spent time with during the weekend trip, it appeared to have a very special meaning and a great importance to them. For some of the participants, it was the first time they had participated; and even after having participated in only one trip, it made a significant impact on them.

³⁹The Blue Clinic was a treatment facility for drug users that offered a different approach to and treatment of drug addiction. At the time when Emilie Gomart did her research, drugs and addiction were greatly debated in France. Underlying the treatment and legal concerns were assumptions about the autonomy of the subject and its capacity to act; the Blue Clinic had an alternative definition of the subject (Gomart 2004: 87; 2002: 518).

“The state of slavery which befalls the one who does not pay his debts. In the Roman Empire, the debtor became the slave of his creditor and the addict becomes the slave of the addictive drug.”

(Gomart 2004: 85)

Within the established treatment facilities, an addict was required to be clean/abstinent before being able to receive treatment; otherwise, the addict was not a free, autonomous subject. The addict is, in this view, a slave of the drug (ibid.). This implies that the addict is a toy of the drug that *acts* deterministically on the addict, who thereby cannot be-(come) autonomous unless s/he is clean (ibid.: 87). This reveals an *a priori* assumption about the relation between object and subject, which had been the foundation for specialists outside of the Blue Clinic. This illustrates a classical position between the subject (e.g., the addict) and the object (e.g., the drug). The human subject, in the eyes of the specialists outside of the Blue Clinic, possesses essential qualities that will mature over time, and subjectivity is not constructed and achieved. This view suggests that:

“Actors enter the scene already formed and filled to the brim with capacities, intentions and desires. ‘Action’ is then the expression of these inherent properties; for this manifestation to be complete, the entities must be the only actors on stage.”

(Gomart 2002: 519)

The specialists thereby had a specific view of human agency, which was positioned in a dualism between drug and addict (Gomart 2004: 88-89). Following the *biases* of the Blue Clinic allowed Gomart to investigate a different definition of human agency, as well as the relation between subject and object, which did not comply with the ‘negative definition of freedom’ where the actor *cannot* act under constraints; s/he cannot act *with* the drug (ibid.: 89). The Blue Clinic, in cooperation with drug addicts and treatment personnel, came up with another definition of human agency, and thereby also the subject. It defined the subject as constructed or achieved, whereby drugs could become part of the subject’s building blocks (ibid.: 89-91). When defining subjectivity as constructed and achieved, drugs can help the addicted subject to change and thus become able to act; the drugs function as building blocks of the subject. When using this alternative definition, it becomes possible to view substitution drugs like Methadone not as something negative, but as part of what *builds* the subject. In Gomart’s study, defining drugs in this fashion meant that they changed the underlying definition of subjectivity that was present outside of the Blue Clinic. As part of the treatment, substitution drugs could be prescribed and utilized by the addict to act *with*. In this way, the substitution drugs could *induce* the addict into action (ibid.: 94-95). In connection with treatment, it was then possible to view substitution drugs as *generous constraints* that would help the addict.

Following Gomart’s argument, *constraints* such as a drug – or for my purposes, *a weekend trip* and a *specific philosophy* can be something with which an individual acts; thus, they become part of the building blocks of the subject. The constraints can thereby be defined as *generous* because they help the young HIV-positives and induce them into action. From my experiences at the weekend trip and with the insights from my interviews, I consider both the weekend trip and Hawk’s philosophy to be generous constraints because they enable the young HIV-positives to act and/or to think differently about their disease. This will be explored further in the next section.

A dispositif

Initially, it might seem far-fetched to compare HIV-positive youths with drug addicts, but discussions about how a subject is constituted and whether the young people can *act* with *generous constraints* makes Gomart’s study appropriate in this context. In a different study, Gomart and Antoine Hennion investigated how an *attachment* to a specific setting can enable new capacities when subjects *pass through* a material setting: a *dispositif*. The theoretical starting point of viewing the Blue Clinic as a *dispositif* – a

setting where subjects and entities are not pre-defined before entering the set-up – is therefore applicable to the Youth Group’s weekend trip. In their study, Gomart and Hennion compare how drug addicts and music lovers attach themselves and emerge with new capacities (Gomart and Hennion 1999). As such, an attachment can allow the passing entities to emerge with new capacities (ibid.). If the youths attach themselves to the Youth Group, then it is possible that they emerge with new capacities after the weekend trip. I am particularly inspired by Gomart’s method, approach and theoretical starting point for understanding what takes place within the Youth Group, and how the young people enact HIV. Theoretically and analytically, I examine this specific weekend trip as a setting: an *architecture* and a place where certain practices take place (Gomart 2004: 97). In this way, it is a *dispositif* – an entity where “‘that which’ lets them emerge: ‘the material setting’” is *generous constraints* (Gomart 2002: 519-521). The young HIV-positives, the coaches, kitchen helpers, physicians, nurses and all other entities (the socio-material elements that I explore later on) become part of the weekend trip, and thereby the *dispositif* (ibid.: 520-521; Gomart 2004: 97). As in Gomart’s study, I claim that not only the youths but also that *I* emerged with new capacities after having passed through this set-up (Gomart 2002: 521-522).

The Youth Group

Tinne Laursen and Lotte Rodkjær founded the Youth Group because they had experienced in their daily work how adolescents and young people with HIV were a group that did not receive a great deal of attention within the treatment protocols, they did not make requirements for their treatment and, according to both them and the youths, there was not enough time for counselling and guidance in connection with the treatment of HIV-positive youths. The two founders experienced the adolescents and youths as being very lonely and sad. To accommodate their needs, the Youth Group was founded (Laursen and Rodkjær 2009: 3). The Group and its annual weekend trip were established to “create a social network for the youths and adolescents, to educate and counsel the participants, to support the participants in taking responsibility for their own sexual practice and to support them in living with a chronic disease” (ibid.). The Group is funded by private organisations, and the participants do not have to pay for their accommodations, food and activities that are part of the weekend trip, and their travel expenses are reimbursed. The two founders decide who can participate; if an HIV-positive youth or adolescent is not “ready” to participate, then it is out of consideration for the rest of the group. These inclusion and exclusion criteria are based upon how a particular adolescent or youth manages to live with HIV, both mentally and emotionally. Potential participants can thus be excluded if the founders do not find them capable of participating (interview with Tinne Laursen; Rodkjær 2009).

The weekend trip is about receiving medical knowledge about HIV and also “creating a space for fun and spending time together” (ibid.: 3-5; my translation). Through being involved in the weekend trip, the young participants get a ‘time out’ from keeping their disease a secret and experiencing the hardships of being chronically ill. As described in the previous section about stigma, experiences that are connected to being HIV-positive set off an array of actions that require the HIV-positive youths to do a lot of work. The weekend trip is a place where these experiences can be discussed, or where the array of actions becomes unnecessary because sharing one’s secret is a pre-requisite for participating in the weekend trip.

Generous constraints

In this section, I explore the concept of *generous constraints* in order to clarify what they are, how constraints become generous, and how they induce into action. As mentioned, I define the subject as something that one achieves and constructs, and action can thereby be induced by an entity such as a substitution drug; or in this case, a philosophy and participating in a weekend trip. According to Gomart:

“When constraints become inductions rather than obstacles to action, autonomy ceases to be the pre-condition for activity.”
(Gomart 2002: 522).

By subscribing to this idea, I move away from understanding subjectivity as something that cannot be constructed *with* constraints. Constraints *can* function as building blocks and become generous when they are not coercive and do not act deterministically on the subject. The generous constraints are, among others, the tools that Hawk of the Yellow Wind, his wife Monike and the other coach Leif use as a technique or tactic to help the young people overcome the obstacles they experience in connection with being HIV-positive; one of the goals is that this will induce them into action.

Hawk, Monike and Leif all participated in the weekend trip as coaches for the adolescents and youths. During the trip, they passed along Hawk’s philosophy, and talked to the adolescents and youths about how they had been (feeling) and what was happening in their lives. Hawk’s philosophy was initially introduced to the Group’s two founders when they participated in a workshop with Hawk at their jobs. They found his philosophy useful, and thus decided to explore it as part of the weekend trip. I define Hawk’s philosophy and the coaching sessions as *generous constraints* – generous because, for some participants, it ‘induces them into action’; they act with this and emerge with new capacities. Hawk’s philosophy could, however, also be thought of and analysed as a ‘discipline’ (a technique of power) (Gomart 2002: 221) – that is, as a structure where the individual/the HIV-positive youth is oppressed by a procedure that ‘regulates’, ‘masks’ or ‘excludes’ (ibid.). If I had chosen to analyse the set-up in this critical view, then Hawk’s philosophy – as well as the set-up of the weekend trip and the Youth Group – could have been seen as a form of discipline that would regulate the behaviour of the participants, and ‘create’ obedient subjects who behave in a certain way. It should rather be viewed as a power that produces and makes something happen: a ‘generous constraint’ (ibid.). It offers the participants an opportunity to manage their disease differently: they are multiple ways that the Youth Group induces the participants into action. This would otherwise not become apparent.

Warrior or Victim?

As mentioned, the Youth Group’s founders came into contact with Hawk of the Yellow Wind, a Native American from Canada, who has developed a philosophy about how people can position themselves in life: specifically, how they can be either *warriors* or *victims* via their actions. Hawk’s philosophy is thereby positioned in a dualism where an individual can be viewed as a victim or a warrior. However, it is possible for an individual to shift between the two positions – that is, to act as a *victim* in one respect, and to act as a *warrior* in another situation. In general, according to Hawk, individuals will always act as a victim in some situations, but should aspire to act as a warrior. As implied, the philosophy⁴⁰ is presented as a way to regain balance in one’s life after being infected with HIV because this can naturally produce an imbalance (Laursen and Rodkjær 2009: 32). The warrior is a person who sees possibilities and opportunities instead of limitations. A warrior is proactive: someone who does not just passively await action, but one who does something. Furthermore, the warrior takes responsibility and does not blame others. S/he is open, flexible and participates in life, and lives in the present rather than in the past or the future. The warrior also recognizes others instead of judging them. In a problematic situation, the warrior acts before the situation worsens. Therefore, the warrior either improves the situation or resolves the problem (ibid.). The victim, on the other hand, is in opposition to the warrior. S/he is closed, concealed and withdrawn from life; the focus is on

⁴⁰I am using the word *philosophy* for lack of a more appropriate term. Generally, a philosophy is something one adheres to and follows. This suggests a disciplining of the adolescents, but in this section, the philosophy should not be understood as *constraints* that produce obedient, disciplined subjects. Instead, it is used as a *tactic* or a *technique* that ‘induces into action’ and produces the subjects (Gomart 2004: 94-95).

limitations, and the victim is reactive. The victim judges others and blames them, and the focus is on the past or the future. The victim is therefore not present and, as such, life passes by the victim (ibid.).

The weekend trip

The hut was a large yellow brick building, located about 25 meters away from the sea. It consisted of a large kitchen, a large dining area, a more cosy room with sofas and a coffee table. Besides these areas, there were long corridors with sleeping quarters that contained a bathroom and a bedroom with bunk beds and a table with four chairs. Furthermore, other rooms were equipped with chairs and tables; these resembled a classroom. The hut was usually used by boy scouts, but could also be rented by other groups. It was not the most luxurious place, but the location was beautiful, and there was plenty of space for everyone and for the weekend's activities.

(Field diary 2010, edited)

The weekend trip took place in a rented hut; each adolescent or youth was assigned to a room to be shared with a few of the others. The caretakers were the two founders, the kitchen helper, myself and another master's student, who were each in separate rooms. Every year, two participants (nurses or physicians) come along to experience the weekend trip and the activities that take place within the Youth Group. These external participants all work with HIV-positive adolescents or youths at their departments. When they return to their respective hospitals, they are able to pass on this information to other adolescents or youths who are HIV-positive, and thus spread the message about the Youth Group. They also get to interact with the participants and obtain more intimate knowledge about what it is like to be young and HIV-positive. The physician also commented about the most recent changes in the treatment of HIV-patients when the participants were informed about these changes.

Arrival

At the start of the weekend, the participants met up and were transported to the hut's location by either bus or car (depending on where in the country they were coming from). For some of the adolescents and youths participating for the first time, this can entail a great deal of anxiety (Kehlet et al. 2005: 5).

“Friday night at around 6 o'clock. A group of young people are waiting beneath the clock in the main train station in Aarhus. They are each standing on their own, discreetly looking around. Wondering if any of the others are also going on the weekend trip with the Youth Group. Most of all, they want to turn around and go back home again because of the butterflies in their stomachs, but at the same time, they are curious about meeting others who are in the same situation as them: to talk about HIV.”

(ibid.; my translation)

This quote illustrates how much is at stake for the participants; the first-time participants often find it hard and nerve-racking to go away for the weekend. However, the older participants look forward to the trip, and experience great turmoil when they are about to turn 25 and can no longer take part.

Trust

In addition to the aforementioned tools by Hawk, other aspects of the weekend trip have great importance in inducing into action; the weekend trip itself is another example, and it can therefore be termed *generous constraints*. In the following quote, the youths/informants comment on what the Youth Group has meant to them:

Anna, Søren and Morten: Hope, drive, joy, solidarity, energy and strength.

Ditte: But what has it given you, to be more specific?

Anna: You sense each other and understand each other in a unique way. Your family and friends can listen, but they can't understand it 100 % – the same as I wouldn't be able to understand what it feels

like to lose a sister, for example. It is also very special that you meet people that you wouldn't otherwise meet: from different countries, different backgrounds who have different prospects. It is weird that you know the other one is HIV-positive, and then you can be completely open about everything else. There are some things that I don't share with my friends that I can just say here.

Morten: I can get really frightened about how much I tell people here – what if they pass it on? Then I am fucked. But that is also what is so beautiful – you choose to trust everybody. And everybody does that, and that's why it's so strong. We hold each other's hands, and if someone lets go, then everything falls apart.

Anna: And it's not as though you only cry and talk about how awful it is. We also talk about other problems, or what great things have happened in one's life. It sounds as though there is a special love, and there is.

(Morten, Anna, Søren and Ditte/ interviewer)

The weekend trip enables the adolescents and the youths to meet people their own age in the same situation, and thus they do not feel as alone with the disease. As mentioned, most of them keep their HIV-positive status a secret in their regular lives, and do not necessarily know anybody else who is HIV-positive. Meeting other HIV-positive youths and going away on the weekend trip together exposes their secret; the knowledge of this implies that they 'sense each other and understand each other in a unique way', and that if this trust is broken 'then everything falls apart'. The openness about their HIV-status means that they have to trust each other not to pass on this sensitive information; as Morten comments: 'That's what makes it so beautiful (...) and strong'. The weekend trip itself works as a generous constraint simply by enabling the adolescents and youths to meet other HIV-positive people in a safe environment that they themselves are part of creating and maintaining. Anna comments that 'there is a special love', and this love is part of the atmosphere. The set-up of the weekend is built upon accepting each other and including the other participants in the group. The two founders aim to create a space for everybody, and the good atmosphere is maintained by the participants. They have experienced being "the new one"; they remember their anxieties before going on the weekend trip, and the warm welcome given to them by other participants. The next year they participate, they welcome new participants in the same warm and friendly fashion. The set-up thus functions as a generous constraint that reproduces itself because of the founders and the participants.

Life experiences

Ditte: What do you talk about during the weekend trip?

Chris: We shared a room, and we started talking. [Later,] we walked around and we shared a lot of things: How do you approach women and tell them you are HIV-positive? We were sharing how our life is. But some of them also just get together and have fun. (...) In the meeting, we talked about our shared experiences; how is your life going, coping with school and like, 'openness'. Saturday was a big day and also a hard day – you talk, and Hawk came and said a lot of things, then the doctors came and talked. I became friends with some of those who live in Copenhagen. It was quite impressive.

Ditte: Is it different when you talk to them because you have similar experiences?

Chris: Yeah. I think it is good when we meet each other, and we talk about our lives, our experiences (...) and sometimes, you listen to some of the kids and what they have been through, you sit down and then you pick up something from it, and you think, "This will help me in my life, and this is what I have also been through". So you also tell them, and we share ideas and all the fears we have, and all the difficulties we have been through. I don't think we have concrete reasons. (...) We didn't talk about HIV; it is about life experiences. (...) I talked about my life experiences.

(Chris and Ditte/ interviewer)

As Chris mentions, the participants talk about their life experiences and how they deal with being HIV-positive in their everyday lives. Furthermore, these conversations about both their fears and ideas have

induced him into action because he has picked up something from what the other participants have said and used it to assist in his regular life. As mentioned earlier, the participants' sharing of ideas, experiences and fears is part of the activities. This is a generous constraint because it allows the participants to talk about who they are, and how they feel about being HIV-positive.

Change

With respect to change, it becomes interesting to think about what the participants' lives might have been like without the Youth Group:

Søren: I often think how my life would have been if I hadn't joined the Group and met these people. I would have had to endure this, and the only contact with my disease would have been at the check-ups at the hospital. I can't even imagine that at all.

Morten: That's what I think is so amazing about this group and the steps it has taken. (...) I felt like when I first joined: "Fuck, they are sad." That's the first thing I thought.

Søren: But that's the difference. You have from the beginning been like, "It's quite alright and that's just the way it is". Where the rest of us, I think, have been victims, at least the first couple of years.

(Morten and Søren)

As stated, the Youth Group has changed how Søren feels about being HIV-positive – through the weekend trips, he has learned how to handle being HIV-positive and to be less sad. This change is emphasized by Morten's comment about how he experienced the participants as extremely sad when he first joined the Group. Morten has been open about being HIV-positive for a long time, which is not the case for many of the other participants. As Søren's quote indicates, some of them have changed in that respect and have shifted to being warriors instead of victims – in this way, the youths apply Hawk's terms and use them in their everyday lives to explain how they act.⁴¹ It also underlines the changes that Anna, Morten, Søren and Chris have experienced because of the Youth Group. As such, the generous constraints like Hawk's philosophy have induced them into action; furthermore, the set-up of the weekend trip means that they consider the other participants to be their family. These comments all indicate the special atmosphere during the weekend trip, and how it is valued by the participants. It also implies how strongly some of the participants feel about each other:

Jonas: I just want to spend time with them. I can just be there; I can be something for somebody. In the beginning, we met up because of HIV, and now we meet up in spite of it. They are the people I love most in the whole world. It's the ones from the Group because I know that I have their unconditional trust, and that's not something I have with other people in the same way. (...) We know everything about each other, (...) you know how their relationship is going. It's just not things that I share with other people. The same thing goes for my health; it's not something I tell other people about – my CD4 count is such and such.

(Jonas)

A Session with Hawk

During the weekend trip, the coaches introduced Hawk's philosophy to the young people through sessions where they discussed how they were feeling, what issues/problems/situations were important to them at present, and how they have been doing since they saw each other last. They do not necessarily have to discuss problems – it can also be joyous and happy events that have occurred in their lives. I took part in the session with a group of older participants; most had participated before this year, and a few had even agreed to start a process in which they would become mentors for the

⁴¹ The youths thus *attach* themselves to the tactics and techniques of the weekend trip.

younger participants. The group I participated in had already been introduced to Hawk and his philosophy several times, and they continued the work they had already started.

Down one of the corridors in the hut, a room has been rearranged to fit the session with Hawk. The tables have been moved to the sides of the room, and the chairs have been placed in a circle, so all the participants will be facing each other. Stones have been placed in the corners on the floor,, branches with green leaves have been picked and scattered around the room; it seems like nature is inside. (...) A bit later on, I am sitting in a chair with the physician on one side and a participant on the other. Hawk begins with a short introduction, and then he takes a feather in his hand and talks about how he has been since they all saw each other last. He finishes his statement with a resounding “Hoo!” He then passes the feather to the person on his left-hand side, who continues in the same fashion. Every participant comments on how s/he is feeling and has been since last time they met, finishing off with a “Hoo!” and then passing the feather.
(*Field diary, October 2010; edited*)

As described, one of the techniques for inducing the adolescents and the youths into action is Hawk’s philosophy, which is introduced via sessions on the weekend trip. During the session I participated in, the young people first explained what had happened to them since last time they met, with respect to problems they had had encountered or good news about what had happened in a more pleasant way.

Pleased about HIV

Anna: That is something I would have never thought when I was told [that I was HIV-positive]. Then, I just thought I was going to die. I thought everything was negative, and that I would have to take what I could get. Even if it was some disgusting guy who wanted me, then I would just have to be happy.

(informants laugh)

Anna: That was my thought at the time, but because of the process I have been through, and primarily because of the Youth Group, it’s meant that I am – it sounds sick but...

Morten [finishing Anna’s sentence]: You are pleased about being HIV-positive?

Anna: I just think that I can mention many more positive things [about] being infected than negative.

Morten: I think that is important to get across. “You feel bad about being HIV-positive or what?” “No, I feel fantastic”.

Anna: It sounds really strange because at the same time I wouldn’t wish [this] on anybody else. (...) But the way my life is now – anyway, it has given me more than it has taken from me, I think.

Søren: (...) For me, it has been the best decision I ever made – it was to agree to go on a weekend trip.

Morten [adding to Søren’s answer]: – was to not use a condom.

(informants laugh)

(*Anna, Morten and Søren*)

As mentioned in this section’s introduction, Hawk of the Yellow Wind has a specific view on how to live one’s life, and this is applied in the Youth Group. One of his phrases is: HIV is a gift. In connection with this, the participants are encouraged to look at all the positive things that HIV has brought into their lives. In the above quote, it becomes apparent how some of the youths have changed their attitude toward what they expect out of life. In Anna’s case, she initially did not think that she would be able to get a boyfriend – and if she was lucky enough to find someone, then she would have to settle, no matter how disgusting the guy was. In the section about stigma, I described how it became apparent that the HIV-positive youths are afraid of being rejected by a partner, and that they sometimes hold themselves back in this respect; furthermore, they have also changed their views through the years on how they feel about being HIV-positive. They become capable of viewing HIV as

something that is mainly positive. It thus becomes possible to sarcastically say that the best thing they ever did was *not* to use a condom. In relation to seeing HIV as something positive, Hawk's statement that HIV can be a gift is provocative.

Hello, HIV cannot be a gift

Chris: When I heard it, I was like, "Hello, HIV cannot be a gift." I disagreed with [Hawk] (...) and he said, "Just go back and look at your life when you were not HIV-positive or [when] you didn't know – did you feel different?" And I can say in my life: Yes, it has been a gift to me.

Ditte: In what way?

Chris: I didn't even dream of coming to Denmark, I didn't dream of living here and getting my life together, having lovely people around me who I can always talk to. When I was in [xx] I didn't have a mother, and now I have a Danish mother who is so dear to me. And it has opened so many things in my life. When I told my friends, they told me, "Hey, we want to bring you here", so that's what they did – they brought me to Denmark. Then I did the study, and it has really been a gift. If I didn't know [my status], maybe I would die or I would struggle.

(Chris and Ditte / interviewer)

In this connection, it becomes clear how Chris has emerged with a new capacity: He can view HIV as a gift. He explains all the great things that have occurred *because of* HIV, not despite it. During the sessions with Hawk and by enacting HIV differently, HIV becomes something that has enabled important changes in Chris's life. In this respect, experiencing HIV as something positive is enabled by Hawk's philosophy and through the coaching sessions. Instead of focusing on the limitations HIV has brought about in Chris's life, he is capable of seeing all the positive effects it has had.

Chris changes his focus, but in order to fully comprehend this capacity, I must clarify some events that occurred in his life. While volunteering for an organisation centred on gay people (and in this connection, also HIV and AIDS), it dawned on him that he could also be HIV-positive. Chris was tested and diagnosed as HIV-positive. Through his volunteer work, he was sent to Denmark to study, and he told his new Danish friends that he was HIV-positive. After studying, he was sent back to his home country but wanted to return to Denmark because he had fallen in love with a Danish girl. His friends helped him to come back to Denmark later, where he has also found a new Danish "mom". In comparison with Chris's life before his diagnosis, HIV becomes, surprisingly, something that is not negative or problematic: HIV becomes a gift.

Being a warrior

It is not HIV in itself that is a gift, but all the positive events that it is connected to and that have occurred because of HIV. This induces Chris into action and makes him feel differently about being chronically ill. It also helps him to live with HIV in a way other than before he joined the Youth Group. In the following quote, Chris explains how he felt before, and how he used (and still uses) Hawk's philosophy:

Chris: When I went to the Youth Group, Hawk asked so many questions and he talked a lot, and I shared my experiences: How I feel angry all the time, and I am a victim and I will always be a victim. So he encouraged me and [said], "You can be the victim, but you have to be the warrior – you have to stand up." I am going through this, and it helps me a lot.

Ditte: But do you still use it today?

Chris: I wrote it down, so any time I feel like refreshing my mind, I just pick it up and read it and say "OK".

(Chris and Ditte / interviewer)

Chris also felt angry and guilty, but in the session with Hawk, he was encouraged to position himself differently in life and to be a warrior. This quote also suggests how the youths become *induced into action* and thus act differently. In these shifts, where the youths go from being a victim to a warrior, or to viewing HIV as a gift, the phrase “induced into action” should not be taken too literally – the action can also be feeling and thinking differently about HIV.

Hawk has a concept where he focuses on what an individual assumes; for instance, if a youth is afraid of telling somebody about their disease because they don’t know how this person will react, they use their assumptions to make up a story or imagine a scenario where the person might have a negative reaction. Throughout the sessions, they are encouraged to not assume anything, but rather to act. In some respects, the youths are in an ambivalent position where on one side, HIV is the worst thing they could imagine; and on the other side, it has become something positive or a strength:

Søren: (...) There is a general attitude – at least that we have discussed in the Youth Group many times – that the worst thing we could imagine was to infect someone else, to put someone in the same position that we have been in. I wouldn’t want that for my worst enemy.

Morten: No.

Søren: That’s also what is paradoxical about it. Because in many ways, now that I have come out on the other side of it, I have a stable life and a partner who knows and who is OK with it. In many ways, it has become a strength for me, actually.

Morten: What?

Søren: Well...

Morten: That you have HIV or what?

Søren: Yes, it has changed my life completely, but...

Morten: *I know where you are coming from.*

Søren: But prior [to that], when it was just something negative – there are so many ways that it is something positive to me now.

(Morten and Søren)

Both Søren and Morten agree that HIV has become something positive, despite the life-changing experience it has been for them as well. As Søren states: “There are so many ways that it is something positive to me now” – this is similar to Chris, because Søren and Morten have also become capable of thinking of HIV as something positive. In earlier quotes, it is evident how Morten has not been as sad as Søren about being HIV-positive; this is apparent in how he felt when he met the other participants in the Youth Group (see page xx). Because the weekend trip is of great importance to the youths, it can be difficult to leave to go back home. This underlines the importance of the trip and the network the youths are part of.

Waiting a whole year

Søren: Before, when I wasn’t so psychologically strong, it was really important with the weekend because I could live an entire year from it. And previously, I was really worn out for a week afterward because I was so upset about not getting to meet up with people for another year.

Morten: That’s what I think is so fantastic – it was only after the first two weekend trips that I cried afterward. The third time and the following ones, I have had so much energy that I wanted to use on the Youth Group and nothing else. I think the year passes by quickly, but that is also because we have the Facebook group. You don’t have to talk every day to know that people are there for each other. I think that’s the strength about the Youth Group – that we know that, no matter what, all you have to do is call.

(Søren and Morten)

Summary

In this section I have analysed how HIV can become a gift, how it can shift into being a disease which has affected the youth's lives in positive way. In the first part of the analysis I focused on how HIV was diagnosed and how the different medical elements became part of the youth's lives. Being diagnosed with HIV and afterwards deciding to tell people about or keeping it to them selves. The first fear and anxiety of being HIV – positive was addressed within the consultation. Later the youths check-up were examined and the lack of time illustrated how the self – care of the chronic HIV-patient was also something which occurred outside of the treatment facilities. Elements such CD4 count, viral load and at some point medication were introduced. These elements proved not just to be one thing but could be enacted differently by the youths. As such medication enacted as a structure in their lives, it however also be a viewed as a magic pill that keeps HIV at bay. In the second part of the analysis the social lives was the focal point – which showed how stigma and different modes of ordering can occur. In the different situations HIV was seen as problematic or just as a chronic disease. All these different versions are part of the activities in the Youth Group, as an overall aim the founders and participants want the weekend trip to function as a place were treatment, social life and other parts of their lives can be discussed. The set-up of the annual weekend trip functioned as a generous constraint which induced the participants into action. The talk between the participants, the friendships that were established and the use of a specific philosophy enabled the youths to view HIV as a gift and as something positive. They became capable of seeing great things which had happened because of HIV and not despite of it. The building blocks which acted as generous constraints allowed the participants to emerge with new capacities. By writing a eulogy and following the biases of the Youth Group it became possible to see how HIV could be transformed into a gift.

Conclusion

This thesis has illustrated how young people in Denmark live with HIV. In the prologue, I described three steps that would situate the context of this thesis. First, I defined HIV as a chronic disease because of the profound developments in medication that have occurred since HIV was first discovered in the early 1980s; second, I focused on a particular group of people, young HIV-positives in Denmark; and third, I examined HIV not as single disease but as a multiple that is performed in different versions.

With this positioning, I wanted to transgress the dichotomy between focusing on illness or disease, and thereby engage in a performative approach to analyse this topic accordingly. Instead of viewing HIV as a single condition from either a medical perspective (disease) or the patients' perspective (illness), I wanted to explore how HIV could be seen as multiple when its practices are the main focus. Thus, by viewing HIV as multiple, it became possible to describe, define and analyse different versions of HIV.

In the first part of my analysis, utilising Annemarie Mol's concepts of multiplicity and enactment (Mol 2002), HIV was enacted in different versions at the treatment facilities, and the diagnosis of HIV was shaped by three different versions of HIV. This emphasised how the definitions of risk groups and 'at-risk behaviour' were incompatible with how the informants felt. They did not consider themselves to be at risk for being infected with HIV, and they were very surprised when they tested positive. The diagnosis also showed how, despite being a chronic disease, HIV is something the informants (mainly) keep a secret or only reveal to their closest friends and family. Furthermore, it showed how a check-up (*clinical version*) was enacted, and how many different elements were involved in it besides just the physician and the patient: for example, an intern, the patient's journal, a physical examination, jokes, a discussion about viral load and medication. The diagnosis also pointed out how elements such as CD4 count, viral load and medication become part and parcel of the young HIV-positives' everyday lives. The CD4 count could thus be both an incentive toward achieving/maintaining a healthy lifestyle and a barrier against it. Furthermore, it could be something that the youths competed over; e.g., who had the highest number. But it could also be a number that fluctuated over time, and thus something that they could not "believe in" or emphasise too much. Implicitly this explored how different elements e.g. CD4 count, medication and viral load affected the youths, and how one cannot describe the patients disease in a linear progression where the patient gradually becomes more and more accustomed to being HIV-positive; instead, it can be characterised as different practices that are dissimilar in how they affect the lives of the young HIV-positives (Mol 2008: 64). In general, this section explored what is required of a chronic HIV-patient as well as the effort, time and emotional feelings that are involved in being HIV-positive.

The second part of the analysis continued to focus on how HIV is performed in different versions, but my attention shifted to the youths' social lives – specifically, how HIV affects their inclination to enter into relationships, when and who they should tell that they are HIV-positive, and how these experiences have impacted them. Here, HIV was explored through modes of ordering (Law 1994), which made it possible to define and describe three modes: silence, openness and karma. All three modes could be imputed to the social lives of the young HIV-positives, and they illustrated recursive ideal types that defined 'the perfect agent'; thus, it was shown how agency could be understood within all three modes. Silence highlighted how the youths keep HIV a secret, and how telling lies and keeping track of who they told what organises their lives. In this respect, HIV was seen in a negative light as something that was self-inflicted and connected to specific groups of people, such as gay men, prostitutes or people from parts of Africa. The concept of stigma and the fear of recognition (Goffman 2009; 1990(org. 1968) were closely connected to this mode of ordering. It helped to explain why the youths chose not to tell their friends, family or partners about having HIV. Openness was in opposition to silence, and in this mode the youths were open about HIV – they were not afraid to tell people about their disease, and the fear and anxiety from silence was not in play here. A negative repercussion, such as not being recognised, is not something that this 'perfect agent' worries about.

Here, HIV was seen as a chronic disease like any other (e.g., diabetes), and thus something that could be shared with others and not kept a secret. The last mode, karma, illustrated how the youths feel they have to tell people that they are HIV-positive in certain situations, such as when they become intimately involved with a new partner. Here, what is at stake is treating others as one would like to be treated. Each of these modes of ordering served to hold my analysis within the performative framework, and helped to define different versions of HIV in the social lives of the youths. Furthermore, the modes served to illustrate in what situations the youths performed the different modes and, most importantly, why. This section also described how much being HIV-positive affects the youths' social lives.

The third and final part of the analysis took a closer look at the Youth Group and its annual weekend trip. Here, the weekend trip was defined as a *dispositif*, a setting or an architecture where certain practices take place (Gomart 2004). I was able to further define the subject as constructed and achieved, and thereby demonstrated how the specific philosophy and the set-up used during the weekend trip can induce the HIV-positive youths into action, which serves as building blocks of the subject; i.e., the HIV-positives. By writing a eulogy and following the biases of the conditions of the Group set-up, I was able to describe how HIV can be a gift. Furthermore, through their participation in the weekend trip, it became possible for the youths to see HIV as something positive. Besides the philosophy used, the set-up of the trip had a great impact on the youths' lives: because they participated in the Youth Group, they found friendships, support and understanding – elements that helped the youths and allowed them to acquire new competences.

With this thesis, the concept of the 'active patient' seems appropriate, especially when one takes into account all of the effort and time these young patients spend on being HIV- positive. Not only do they have to handle being diagnosed and what this means, but the chronic patients have to go to check-ups for the rest of their lives and take medication for a great deal of it. As illustrated, managing this part of the disease is not straightforward, but the youths do not wish to be seen as passive, suffering patients. In many ways, they are patients, but they also fight for their right to be seen as merely HIV-positive and not allow the disease to define other aspects of their lives.

List of literature

- Aull Davies, Charlotte 2008 [1998]. *Reflexive Ethnography*. London and New York: Routledge.
- Dahl, anders & Mie Carstensen 2007: *Levekår og livskvalitet blandt hiv-smittede i Danmark*. Sundhedsstyrelsen. København. 2007
- Binder, Brandt and Gregory (ed.) 2008. Design participation(-s). *CoDesign* 4(1), March 2008.
- Epstein, Steven 1996: 'The Discovery of a "Gay Disease" (1981-1982)'. In: *Impure science. Aids, Activism, and the Politics of Knowledge*. USA. University of California Press
- Gazzard, B & Jones, R.S.2006 : From death to life: two decades of progress in HIV therapy. In: *HIV/AIDS in Europe Moving from death sentence to chronic disease management*. København Europe WHO.
- Goffman, Erving 2009: *Stigma. Om afvigerens sociale identitet*. Frederikberg. Samfundslitteratur.
- Goffman, Erving 1990(org.1968): *Stigma. Notes on the Management of Spoiled Identity*. England. Penguin Books.
- Gomart, Emilie 2004:'Surprised by Methadone: in Praise of Drug Substitution Treatment in a French Clinic'. In: *Body & Society* 2004:10:85-. Sage publications
- Gomart, Emilie 2002: 'Towards generous constraints: freedom and coercion in a French addiction treatment'. In: *Sociology of Health & Illness*. Vol.24. No.5.pp 517-549
- Gomart, Emilie & Hennion, Antoine 1999: 'A sociology of attachment: music amateurs, drug users'. In: John Law & John Hassard 1999 (ed.): *Actor Network Theory and After*. Blackwell Publishing/The Sociological Review.
- Harris, Magdalena 2009: *Injecting, infection, Illness: Abjection and Hepatitis C stigma*. Body & Society 15:33. Sage Publications
- Jensen, Torben Elgaard 2001: *Performing Social Work Competence, orderings, spaces and objects*. Ph.D. Department of Psychology, University of Copenhagen.
- Ibid. 2003: *Aktør-Netværksteori – en sociologi om kendsgerninger, karakter og kammuslinger*. Papers in Organization No. 48. Copenhagen Businessschool.
- Jespersen, Astrid Pernille 2007: *Engagement i arbejdet? Konsultationsprocesser hos danske praktiserende læger*. Ph.d.-afhandling, Saxo-instituttet, Afdeling for Etnologi. Københavns Universitet 2007.
- Jespersen, Astrid Pernille & Breddam, Mads Dupont 2010: 'Surfing Conversations. The development of a methodological approach to the Internet as practice'. In: *Nätverket* nr 17, 2010 pp.15-32
- Järvinen, Margretha & Nanna Mik-Meyer 2005: *Kvalitative metoder i et interaktionistisk perspektiv*. København. Hans Reitzelsforlag.

- Kehlet, Jakob 2005: *Unge med HIV*. Frederiksberg. Forlaget Her & Nu.
- Kehlet, Jakob 2006: *The group of young HIV positives*. Denmark. Rosenberg Bogtryk
- Labaree, Robert (2002) The Risk of Going Observationailst: Negotiating the Hidden Dilemmas of Being an Insider Participant Observer. In *Qualitative Research*. 2(1):97-122.
- Laursen, Tinne & Rodkjær, Lotte 2009: *10 år med Ungegruppen. Rapport om Ungegruppens aktiviteter i 2009*. Ungegruppen – for hiv-smittede mellem 15-25 år.
<http://www.ungegruppen-dk.dk/data/images/ungegruppen%20rapport%202009.pdf>
- Laursen, Tinne, Rodkjær, Lotte, Anne W. Ravn, Hanne Arildsen, Carsten Schade Larsen & Henning J. Sællænder: *At leve med hiv, en bog til patienter og pårørende*.
 Book handout from Aarhus University Hospital: Skejby. Afdeling Q.
- Law, John 1994: *Organizing modernity*. Oxford UK & Cambridge USA: Blackwell Publishers.
- Mol, Annemarie 1999: 'Ontological politics. A word and some questions.' In: John Law & John Hassard 1999 (red.): *Actor Network Theory and After*. Blackwell Publishing/The Sociological Review.
- Mol, Annemarie 2002: *The body multiple: ontology in medical practice*. Durham: Duke University Press.
- Mol, Annemarie 2008: *The Logic of Care. Health and the problem of patient choice*. London & New York: Routledge.
- Marcus, George E. 1995: 'Ethnography in/of the World System. The Emergence of Multi-Sited Ethnography'. In: Marcus, George E. 1998 (red.): *Ethnography through Thick and Thin*. New Jersey: Princeton University Press.
- Nanna Mik-Meyer 2009: Sundhed i et sociologisk perspektiv: moralens indtog. In: Helder & Hagel: Sundhedsledelse - forudsætninger, teori, perspektiver. Hans Reitzels Forlag
- Nielsen, Jens-Emil 1994: *Det farlige begær om sex i en AIDS tid*. Fredriksberg Her & Nu
- Olesen, Finn 2010: Den forstærkede patient-Om patientbegreber og empowerment. In: Jensen, Uffe Juul (ed.) et al. 2010: *Viden, virkning og virke-forslag til forståelser i sundhedspraksis*. Frederiksberg. Roskilde Universitetsforlag
- Sandberg, Marie 2009: *Grænsens nærvær og fravær Europæiseringsprocesser i en tvillingeby på den polsk-tyske grænse*. Ph.d -afhandling , Saxo-instituttet, Afdeking for Etnology. Københavns Universitet 2009
- Sundhedsstyrelsen 2006: *Patienten med kronisk sygdom. Selvmonitorering, egenbehandling og patientuddannelse*. Et idékatalog. Islandbrygge. Scantryk
- Vallegårda, Signild 2003: 'Tvang og tillid i AIDS-forebyggelsen. In: *Folkesundhed som politik. Danmark og Sverige fra 1930 til i dag*. Århus. Aarhus Universitetsforlag

Villadsen, Katrine Weiersøe 'Jeg vil bare gerne leve et helt almindeligt liv' : hverdag med hemmeligheder, frygten for stigmatisering, uvished og ønsket om børn blandt en gruppe HIV-smittede i Danmark / af Århus : Aarhus Universitet, Afd. for Antropologi og Etnografi, 2008

Internet

The Youth Group in Danish
<http://www.ungegruppen-dk.dk/>

The Youth Group in English
<http://eng.ungegruppen-dk.dk/>

Project and service department
<http://samf.ku.dk/pkv/english>

HIV travel database
<http://www.hivtravel.org/Default.aspx?pageId=150#report>